PSYCHOLOGICAL FACTORS AND QUALITY OF LIFE:
A PROSPECTIVE STUDY OF CARDIAC
TRANSPLANTATION RECIPIENTS

By

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

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The purpose of the present study was four-fold: 1) to provide

descriptive information about the prevalence of immunosuppressive

symptomatology and quality of life of cardiac transplantation recipients, 2)

to test the predictive validity of a pre-transplantation psychological

assessment battery on the recipient's ratings of post-transplantation quality

of life, 3) to test the predictive validity of the pre-transplantation

psychological assessment battery on the spouse/proxy ratings of post-

transplantation quality of life, and 4) to assess the correspondence of the

patient and proxy raters on quality of life.

Results indicated that on average, cardiac transplantation recipients

commonly experience approximately 10 immunosuppressive symptoms;

fatigue and mood swings were noted as particularly problematic by the

recipients and spouse/proxies. Following the formation of four cluster groups of pre-transplantation MMPI profiles, tests of significance found no differences in the quality of life variables between cluster groups. Regression analyses were also used to test the predictive validity of the other pre-transplantation medical and psychological variables. Results from these analyses found that trait anxiety was a significant predictor of increased symptom frequency and symptom problems, and decreased mental health. Similar results were found using the spouse/proxy reports, such that trait anxiety was again a significant negative predictor of mental health functioning and satisfaction with life. Taken together, trait anxiety emerged as a diverse predictor of post-transplantation quality of life functioning, as viewed from both the recipient and spouse/proxy perspectives. Finally, results from correlational analyses between recipient and spouse/proxy reports yielded generally high correspondence, but planned comparisons found significant differences in mental health functioning, with spouse/proxies rating the recipient's mental health lower. Collectively, modest support for the use of pre-transplantation psychological variables as predictors of post-transplantation quality of life was found.

INTRODUCTION

Cardiac transplantation has rapidly emerged as a viable treatment option over the past decade. The discovery of reliable immunosuppression drugs that decrease organ rejection episodes has made cardiac transplantation the treatment of choice for individuals diagnosed with end-stage cardiac disease. The research on longevity in the vast majority of recipients suggests that cardiac transplantation extends the length of life (Mai, McKenzie, & Kostuk, 1990). Therefore, cardiac transplantation is expected to become a widespread procedure in future health care that may be limited primarily by the availability of donor organs. Because longevity of cardiac transplantation recipients is now established, researchers and health policy administrators have also begun to consider outcomes in terms of quality of life post-transplantation. Although much disagreement exists about the definition, measurement and theoretical basis of quality of life, initial investigations of post-transplantation quality of life have agreed that the recipients that survive the transplantation waiting and initial post-operative periods have significant improved quality of life from pre-transplantation to post-transplantation (Jones, Taylor, Downs, & Spratt, 1992; O'Brien, Banner, Gibson, & Yacoub, 1988). As a result of these studies, Freeman, Folks, Sokol, and Fahs (1988) have suggested that "the most important clinical research question concerns quality of life following

1

cardiac transplantation" and research should "continue to examine which assessment and management techniques are beneficial to the cardiac recipient in an attempt to identify clinical and demographic characteristics that predict an enhanced quality of life" (pp. 53-54).

The current study was a longitudinal investigation of cardiac transplantation recipients of Shands Hospital. Telephone interviews were used to assess the self-perceived quality and satisfaction of life of each recipient. Additional ratings of the recipients' quality and satisfaction of life were collected by sampling the responses of the recipient's spouse or significant other (proxy) on similar measures. Interview responses from the cardiac transplantation recipients and their spouse/proxies were then merged with information from the pre-transplantation medical and psychological evaluations that are routinely performed as part of the candidate selection process. This joining of information allowed for the examination of pre-transplantation medical and psychological variables that were associated with desired post-transplantation outcome in terms of quality of life. Possible differences were examined between established personality clusters of cardiac transplantation candidates (Robinson, Greene, & Geisser, 1993; Hecker, Norvell, & Hills, 1989) in the dimensions of quality of life. Follow-up regression analyses were performed to find variables that may serve as useful "markers" of successful post-transplantation quality of life. Data from this project will be very helpful to transplantation teams in planning interventions with transplantation candidates in order to ensure the highest quality of life possible for each patient at post-transplantation.

REVIEW OF THE LITERATURE

As recently as 15 years ago, the diagnosis of end-stage cardiac disease provided the patient with few treatment options and imminent death. Cardiac transplantation was considered an experimental procedure that was rarely performed. Prior to 1980, the Registry of the International Society for Heart Transplantation listed only 360 recipients worldwide (Kriett & Kaye, 1990). The discovery of reliable immunosuppression drugs, such as cyclosporine, sparked a dramatic increase in transplantation centers from 8 in 1980 to 149 in 1989 and a dramatic increase in transplantation recipients that eventually resulted in an organ shortage (Kriett & Kaye, 1990).

National statistics indicate that the most common diagnoses in cardiac transplantation candidates are cardiomyopathy and coronary artery disease (Kriett & Kaye, 1990). Cardiomyopathy refers to a set of disorders that includes structural or functional abnormalities of the heart muscle (Mersch, 1985). Coronary artery disease is an atherosclerotic process that involves a thickening of the intimal layer of the blood vessel wall which allows for the accumulation of occluding lipids and manifests itself in four major clinical syndromes: angina pectoris, myocardial infarction, heart failure, or sudden death (Brannon, Foley, Starr, & Black, 1993). The family of cardiomyopathies important to transplantation include ischemic, idiopathic, viral, and dilated. Ischemic cardiomyopathy refers to the lack of oxygen

3

supply to cardiac tissue usually due to the presence of coronary artery disease. Idiopathic cardiomyopathy refers to cardiac muscle cell death due to unknown causes. Some researchers believe that some of the unknown causes of idiopathic cardiomyopathy may be undetected viruses (Lorell & Braunwald, 1992). Viral cardiomyopathy is the inflammation of the visceral and parietal pericardial membranes due to the presence of many common viruses that cause such diseases as mumps, chicken pox, mononucleosis, and influenza. Dilated cardiomyopathy refers to the enlargement and impaired systolic function of one or both ventricles (Wynne & Braunwald, 1992). The end-result of these cardiomyopathies often is congestive heart failure which is characterized by the inability of the heart to maintain an adequate cardiac output to meet the demands of tissue. The symptom presentation may include shortness of breath, cardiac pain, and lethargy. The ability of the heart to perform its work is captured in an expression known as an ejection fraction. The ejection fraction is a global index of the extent of ventricular fiber shortening and is thought to be a useful measure of overall left ventricular pump function (Braunwald, 1992). The average ejection fraction for adults is .67 $\pm$ .08, while the ejection fraction for end-stage cardiac disease patients is less than .20.

Because historically only palliative care existed for patients suffering from end-stage heart failure, much excitement was generated by the potential to become a transplantation center in the mid 1980's. The growth of transplantation centers was managed by the National Organ Transplantation Act of 1984 which required centers to maintain rigid

selection criteria and success rates to become transplantation centers. The establishment of multi-disciplinary teams of health professionals has become an important element to both the pre- and post-transplantation periods by aiding in selection and follow-up care. The survival rates in the post-transplantation cyclosporine era appear to be encouraging with 1 year longevity ranging from 83-95% (Kriett & Kaye, 1990). Recent follow-up data indicate that approximately 60-70% of patients are still alive after 5 years (Kaye, 1993).

A major area neglected by researchers in cardiac transplantation is the consideration of individual differences. For example, the differential effects of gender on the presentation, consideration, and receipt of cardiac transplantation remains a generally unexplored area. Research on women and general heart disease also appears limited and usually involves the generalization of research findings from studies of men to women. Eaker (1989) reviewed the psychosocial characteristics that have been studied in women with heart disease and found little evidence for generalizing findings from studies of men to women. For example, Eaker concluded that constructs such as Type A behavior, a competitive, ambitious, and hard-driving lifestyle, do not seem to be related to the incidence of heart disease but may be related to chest pain symptomatology. Haynes and Czajkowski (1993) drawing on more recent research drew tentative conclusions about other psychosocial risk factors. These authors concluded that a strong inverse association between education level and heart disease exists for women. In addition, suppression of anger and lack of social support appear

to be somewhat linked to heart disease in women. More importantly, these authors continued to emphasize the lack of sufficient research with women with heart disease. The problems of insufficient sample sizes in studies with women with heart disease are magnified in the cardiac transplantation literature because of the already small potential samples of cardiac transplantation recipients. It is suggested that as the prevalence of cardiac transplantation progresses, research attention to the specific needs of women in transplantation will be necessary to provide a more complete understanding of the effectiveness of protocols for women.

Stages of Cardiac Transplantation

Clinical experience with the heart transplantation candidate over the course of care has indicated that stages exist that require differing demands of the patient. A number of researchers have provided overviews of the stages of cardiac transplantation (Kuhn, Davis, & Lippman, 1988; Mischel & Murdaugh, 1987). This section will summarize the stages of cardiac transplantation as they relate to the subjects of the current study. It should be noted that these stages represented anecdotal experiences of clinicians that have worked in this area rather than stages that have been empirically validated.

Diagnosis and Decision Making

The diagnosis of a life-threatening condition naturally elicits a variety of reactions such as anxiety, mood disturbance, panic and fear. The announcement of the diagnosis requires the person to accept that their condition is terminal and, in most instances, confront their own mortality.

The amount of time available for this acceptance process is variable; some patients have a period of months or even years to adapt, others have just a few days. In a paper presented to the American Psychological Association (1992), Greene reported that the average number of months of illness for cardiac transplantation candidates was 77.16 (sd = 90.37) but the range was 1-660 months. Some researchers have speculated that a relationship between onset of cardiac difficulties and psychological distress exists such that patients with rapid onset of cardiac disease (e.g. viral cardiomyopathy) exhibit more psychological difficulties (Freeman et al., 1988). To be considered a cardiac transplantation candidate, the patient must be classified in class 4 (patient exhibits discomfort at rest) of the New York Heart Association classification system. If the experience of cardiological difficulties is long-term, the patient may have become resolved to a premature death. Following the acceptance and/or consideration of the severity of the diagnosis, the patient and his/her significant others are faced with the decision to pursue transplantation. The transplantation alternative is an object of approach-avoidance for the patient that often brings thoughts and concerns of the negative side effects of the transplantation such as rejection, continuous medical follow-up, and possibly death.

Proceeding with the Candidate Selection Process

After acknowledging the terminal diagnosis and deciding to proceed with the transplantation program, the pre-transplantation assessment begins. This stage's importance is underlined because it is the period in which all possible relevant information should be obtained for the purpose of

preparation. Unlike some other areas of medicine which treat difficulties once they arise, the transplantation program must <u>prevent</u> or <u>foresee</u> major impediments to the procedure or to recovery. More clearly, trained health professionals must make every attempt to identify the stressors and resources of a patient and significant others. Many national transplantation centers have indicated the use of a multi-disciplinary team for assessment (Kay & Bienenfeld, 1991). The assessment of coping requires a comprehensive review of the patient's environmental system as well as their own personal resources. Anecdotally, it would appear that at the very same time the stressors are at their peak, transplantation candidates' resources are at their most diminished point. Supplementary resources must be integrated into treatment to minimize complications and setbacks. Therefore, the multi-disciplinary approach is useful to provide an assessment of all possible resources and stressors for the patient.

The pre-transplantation evaluation represents another significant step for the cardiac transplantation candidate. Patients are faced with the task of invasive medical diagnostic procedures and repeated interviews. At Shands Hospital, candidates and their families are interviewed by a psychological team, a social worker, and a pastoral counselor. Each of these evaluations include the disclosure of personal information. In addition, psychological test batteries are performed to compare the candidate to a normative sample of cardiac transplantation candidates. The patient's responses and perseverance through these evaluations often serve as important examples of the patient's potential future interactions with the transplantation team

members. These evaluations can sometimes be "in vivo" tests of the patient's ability to comply with the medical regimen. The demand characteristics of the evaluation for the patient may be perceived as attempting to present yourself in the best possible light, so as to facilitate the patient being "listed" on the organ availability list. Current general contraindications to transplantation include over age 65, being diagnosed with cancer, an active infection, Type II Diabetes, severe vascular disease, renal dysfunction, or a psychosis (Braunwald, 1992).

The Waiting Period

Although the listing of the patient is certainly somewhat relieving, the waiting period that follows may represent the most difficult time from the patient's perspective. The potential for problems is great. During this stage, many cardiac transplantation candidates experience increased death anxiety which may manifest itself in insomnia due to concerns that the patient may die in his sleep. Anxiety appears to increase in relation to the deteriorating physical health. The patient's anxiety during this period may be warranted because it is suggested that 20-30% of cardiac transplantation candidates expire on the waiting list for available organs (Braunwald, 1992). Another difficulty for transplantation candidates is disease-related dementia. In absolute value terms, these conditions represent mental status decline, thus, a further depletion of resources that are already taxed. Difficulties with information comprehension and memory impairments in encoding and retrieval are often reported. Although little can be done to prevent this condition, the patient and family may be aided by the education components

that are a routine part of the previous stages. The patient and his family can often recognize these symptoms instead of experiencing alienation and anxiety about a medical decline. Other common problems for the transplant candidate includes the 24 hour "on-call status" for notification as to the possibility of transplantation. However, sometimes patients respond to false alarms in which they are paged to report for surgery only to be informed that the available organ was not acceptable for harvesting from a potential donor.

Transplantation and Post-hospitalization

Because much work has been performed to arrive at transplantation, the actual transplantation surgery can be anti-climactic. The primary difficulties with surgery are the post-surgical complications both medically and psychologically. The surgery is usually performed on someone whose condition was not very good and the waiting period often drains a patient of his immediate resources. Medical difficulties include problems with tolerating the surgery and the subsequent biopsies. There are currently no non-invasive techniques for detecting rejection of the transplanted tissue. Transplantation recipients must undergo the insertion of a bioptome through their right jugular vein and small samples of tissue are excised (Reitz, 1992). In addition to repeated biopsies, recipients must cope with the various side effects of the administration of immunosuppressive drugs. Lough, Lindsey, Shinn, and Stotts (1987) outlined the most common complications associated with cyclosporine therapy including: renal dysfunction, hypertension, interstitial myocardial fibrosis, and increased susceptibility to infection. The existence of Cytomegalovirus (CMV) appears to be highly

prevalent (Braunwald, 1992). Psychologically, patients suffer from guilt about the death of the donor and sometimes indebtedness to the medical staff for saving their life. Nonetheless, both medical and psychological difficulties represent threats that require coping.

Long-Term Rehabilitation and Recovery

Numerous clinic visits which include hemodynamic measurements and tissue biopsies are required during this period for the purpose of assessing/monitoring immunosuppression levels and possible rejection in the donor organ. Obviously, these visits can be filled with some anxiety about the findings. Restarting life with a transplantation represents its own difficulties. The adjustment for the patient and his family can be monumental. New roles are established and necessitated. Attaining gainful employment is a crucial concern for non-retired transplantation recipients. Some transplantation centers consider return to work as a necessary condition for transplantation (Paris, Woodbury, & Thompson et al., 1992). Social and personal concerns are also highly prevalent. Other people see the patient as a "transplant recipient" and the surgical mask over the patient's face reminds them of their special status. Clearly, body image concerns are also a significant issue for the patient as he/she considers the foreign body parts and scars that are part of his/her new life (Lough et al., 1987). Quality of life concerns became an essential focus of the post-transplant period. Many patients are left with more questions and decisions to make than ever before in their adult life. Once again, problem-solving is helpful in facilitating the patient's adaptation to the new roles and may enhance adherence.

Quality of Life

Conceptualization

The current emphasis on the consideration of quality of life may have begun in 1964 when President Lyndon B. Johnson stated that the goal of The Great Society was "to improve the quality of life" (Barofsky, 1986). Soon thereafter, sociologists and economists led the efforts to define and measure the term "quality of life." Today, theoretical and empirical arguments continue to be waged about the definition, measurement, and implementation of quality of life concerns by a host of academicians and professionals including sociologists, economists, psychologists, and physicians, as well as insurance companies, environmental groups, and public policy contributors. In the health care arena, the emergence of life-saving medical technology has increased the motivation to measure quality of life because these breakthrough treatments may increase an individuals' length of life while not necessarily maintaining or enhancing the quality. This impetus to successfully measure quality of life, however, has not led to any quick answers.

Despite multi-disciplinary efforts to define and measure quality of life, it is apparent that there is no agreed upon definition or operationalization for quality of life. The term "quality of life" has been said to mean all things that one might want to measure beyond the traditional outcomes of death or disease activity (Guyatt, Feeny, & Patrick, 1991). Other researchers have suggested that quality of life measures the difference, or gap, at a particular period of time between the individual's hopes and expectations and that

individual's present experiences (Calman, 1984). Although no agreement

about the definition of quality of life seems to exist, most health care

professionals agree that quality of life is a critical variable to consider in life-

saving treatments.

<u>Measurement Approaches</u>

The major measurement distinction in quality of life research has been

whether to measure it as a single or multi-dimensional variable. Proponents

of the single dimensional approach simply ask patients: "How is your quality

of life?" They argue that rating one's own quality of life is a daily pursuit

when someone asks, "How was your day?" In a sense, the question taps

the quality of a person's life during that particular day. In contrast, the

multi-dimensional proponents have suggested that quality of life

encompasses a variety of domains that can form a composite quality of life

index. These include such areas as activity level, daily self-care, overall

health, marital and family relations, career, spiritual, and religious

satisfaction. Proponents of the multi-dimensional approach argue that these

domains must be measured individually in order to properly sample the

components of one's perception of his/her quality of life. Schipper and

Levitt (1986) have characterized the current conflicts between global and

multi-dimensional efforts by stating, "the more global the definition, the

more abstract, and the more abstract, the less measurable." The authors

concluded "the less measurable, the more scientifically uncomfortable"

(p.20) scientists and researchers become. Presumably because of

arguments such as this, many researchers have tended to be more

comfortable with physiological or biological outcome measures (e.g. left ventricular ejection fraction) because they are seen as more scientifically rigorous and reproducible. Nonetheless, researchers have implicitly continued to measure similar core attributes thought to be associated with quality of life, such as disease symptoms and/or treatment side effects, functional status, psychological distress, social interaction, sexuality and body image, and satisfaction with medical treatment (Aaronson, 1986). MacKeigan and Pathak (1992) recently summarized the practice of measuring the multiple domains of quality of life by tapping into the "5 D's": death, disease, disability, discomfort, and dissatisfaction. They further group these health outcomes into mortality (death) and morbidity (disease, disability, discomfort, and dissatisfaction).

Guyatt, Feeny, and Patrick (1991) have suggested that a resolution to the differing views of quality of life measurement is the inclusion of multiple indices that represent both the uni-dimensional and multi-dimensional paradigms. They suggest that the advantage of multiple measurement is that specific information about a particular domain of interest such as mobility or social activity can be obtained. The more general measurement, in turn, would provide information that may be more generalizable and of interest to policy makers or third party payers. The disadvantages of multiple means of measurement would include potential burden to subjects and possible interpretive difficulties if improvement is shown by some measures but not on others. Table 1 provides a brief listing of the various

types of quality of life measures currently available for health outcome research.

Perhaps the most practical approach to measurement of health-related quality of life has evolved from the early studies of the Health Insurance Experiment funded by the RAND Corporation that sought to measure changes in health, from children to the elderly and from health to illness (Brook, Ware, & Davies-Avery, 1979). Building on the knowledge gained from these early attempts of measuring health, a group of researchers sought to examine the multiple indices of health in a large sample ($\underline{N}$ = 22,462) at over 500 sites in three large cities with the purpose of deriving scales that would meet the diverse definitions and needs of researchers seeking to measure and track changes in health status. The products of these efforts have been a set of scales that measure distinct components of health using both rational and empirical scale development techniques. Thus, the Medical Outcomes Study Health Survey Short Form-36 (SF-36) was derived. The SF-36 assesses 8 domains of health functioning including: physical functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, bodily pain, mental health, vitality, and general health perceptions. Descriptions of each of the scales is available in the Method section. The items and scales of the SF-36 are scored so that a higher score indicates a better health state. Initial psychometric information appears to be encouraging, with appropriate reliability and validity having been established.

Table 1

Quality of Life Measures

Type of Measure	Definition of Measure	Example
Mental Status	Psychological and psychiatric testing intended to assess adaptation, personality, and/or mood.	Mini Mental Status Exam
Functional Status	Measures person's ability to perform activities of daily living (ADL's) or other physical abilities.	New York Heart Association rating
General Health Status	Intended to measure overall personal health and the absence of illness.	McMaster Health Questionnaire
Symptom Checklists	Measures the frequency and severity of somatic symptoms. Some measures are available in disease-specific formats.	Transplant Symptom Frequency and Distress Scale
Life Satisfaction	Intended to measure individual's perceived contentment with life.	Satisfaction With Life Scale (SWLS)
Psychosocial Adjustment	Measures the multiple components that form a composite score of overall quality of life.	Psychosocial Adjustment to Illness Scale (PAIS)
Global Quality of Life	Intended to quantify quality of life into a single quotient.	EuroQoL
Multiple-Domain Health Status	Measures the multiple components of health including physical functioning, mental health, vitality, and role limitations.	Short Form-36 Medical Outcomes Study Health Survey (SF-36)

The differing views about the conceptualization of quality of life have also resulted in different assessment modalities such as self-report questionnaires and clinical interviews. Mayou (1990) suggested that although questionnaires provide quick assessments of quality of life, they may not be as sensitive to individual differences as other measurement techniques. For example, a semi-structured interview would permit more open-ended responding that can allow for both quantitative and qualitative analysis. A brief structured interview would also allow various health professionals to assess an individual's quality of life accurately and efficiently. It is important to note that the reliability of quality of life assessments by questionnaire and interview has been examined (Bremer & McCauley, 1986) and results indicated that reliability of measurement was not affected by location or format. More clearly, the researchers varied the quality of life assessments by whether subjects completed the measures at home or in the hospital and by interview or questionnaire. Their results showed equivalent reliabilities regardless of the setting or mode of response, suggesting that either interview or questionnaire provide consistent quality of life measurement. The validity of the interview could be further established by considering not only the patient's view but also the spouse/significant other's perception of the patient's quality of life.

Mayou (1990) recently critiqued both the conceptual and measurement paradigms of quality of life in the cardiovascular disease literature. He listed the overemphasis on general quality of life as a particular problem, suggesting that general measures neglect important

aspects of quality of life such as mental status, individual satisfaction, and family/significant other satisfaction. Mayou (1990) stated that quality of life should be defined in terms of what is important to the family and "must include a measure of satisfaction" (p. 101). He pointed toward methodological problems such as the reliance on self-report measures rather than interview-based measures and the use of unrepresentative samples.

Following the recommendations of various researchers (Guyatt, Feeny, & Patrick, 1991; MacKeigan & Pathak, 1992), the current study has chosen to employ a multiple measurement paradigm designed to sample from the best of the existing instruments. Quality of life, for the purposes of this study, was simply a general label referring to a lifestyle in which the patient is relatively disease symptom-free, highly satisfied with life, and able to vigorously function with few limitations due to physical or mental difficulties.

Predictors of Quality of Life

Partial support for hypothetical relationships can be gleaned from research in other areas of transplantation and medical procedures that were designed with similar goals of prediction of post-intervention outcome. Although generalizations from such studies should be made cautiously, a brief review of this literature is presented.

Depressive disorders (major depression, organic affective disorder, dysthymic disorder, and adjustment disorder with depressed mood) are generally agreed upon to be a common co-occurrence of significant medical

conditions (Beidel, 1987). The assessment and intervention in depressive symptomatology in transplantation has received the most attention from health psychological researchers. Maricle et al. (1989) reported an incidence rate for depressive syndromes in cardiac transplantation candidates of 54% (37 of 68). Furthermore, Maricle et al., reported that depressive symptomatology was associated with demographic factors such as younger age, less education, lower occupational achievement and previous psychiatric history.

Although depression is widely recognized as a potentially concomitant difficulty for transplantation candidates and recipients, the exact impact on post-surgical outcome remains somewhat unknown. The relationship between depression symptomatology and survival has been investigated. Maricle, Hosenpud, Norman, Pantley, Cobanoglu, & Starr (1991) examined the predictive validity of preoperative psychological distress, as measured by the SCL-90-R, on post-transplantation graft rejection and infection rate in a sample of 58 cardiac recipients. Their results indicated that there was no relationship between the global symptom index and graft rejection and infection rate. However, follow-up analyses without Bonferronni correction indicated that the depression subscale of the SCL-90-R was significantly associated with infection ($r = -.27$). Significant associations were also found with rejection in which anxiety ($r = .31$), psychoticism ($r = .30$), and positive symptom distress ($r = .29$). These correlations were not significant after correcting for the multiple hypotheses. The authors concluded that the SCL-90-R had only limited predictive validity in post-transplantation medical

variables. However, the authors failed to acknowledge that psychological factors would be expected to be more clearly implicated in quality of life outcome measures.

Colon et al. (1991) also studied depression in 100 acute leukemia patients who were undergoing allogenic bone marrow transplantation. Results indicated that patients who reported depression as a prominent symptom at the pre-transplantation evaluation had poorer 1-year survival rates following transplantation. Additional results indicated that patients who were rated as having a high level of perceived spouse/family support were found to have improved survival when compared to patients with low or moderate support. The researchers concluded that depressed mood was a negative "marker" for outcome in bone marrow transplantation patients. In contrast, Maricle et al. (1989) found no relationship between depression and mortality in a small sample ($\underline{N}$ = 43) of cardiac transplantation recipients.

Depression has also been examined as a negative predictor of quality of life. Rodin and Voshart (1987) studied a group of renal transplantation candidates ($\underline{N}$ = 115) classified as depressed on the BDI (scores > 17). Results indicated that depression scores were significantly associated with lower general quality of life ($\underline{r}$ =.59) and more unemployment, even after controlling for relevant demographic factors (Rodin & Vorhart, 1987). Maricle et al. (1989) found a significant trend in long-term cardiac transplantation survivors between pre-operative depression symptomatology

and employment such that 60% of the non-depressed group had returned to work while only 28% of the depressed group were employed. Although moderators of the depression-employment relationship probably do exist, no examination of potential moderators was proposed in this study.

Other studies have begun to investigate potential moderators of the relationship between depression, survival, and quality of life. Conn, Taylor, and Wilman (1991) hypothesized that depression may impact quality of life by depleting energy needed for active coping efforts. The authors studied the impact of mood states on quality of life in a group of coronary artery bypass graft (CABG) patients. Their results indicated that depression scores accounted for 49% of the variance in quality of life scores, however, no relationship was found between anxiety and quality of life. Depression scores were also strongly related to decreased exercise, a poor diet, increased medications, stress, and smoking.

Another interesting hypothesis regarding the presentation of depressive symptoms involves the idea that patients that are the "sickest" from a cardiological perspective would show the most psychological distress. Preliminary studies of this hypothesis in cardiac transplantation candidates, however, do not support this idea. Maricle et al. (1991) found no replicable relationship between cardiac function and report of depressive symptoms. In fact, in a second study, their results indicated that patients that reported the most depressive symptomatology had significantly better cardiac indices. These findings suggest that distress is associated with

patients who have improved cardiological output. These findings are consistent with another study of cardiac patients in which higher anxiety was associated with better cardiac output (Schocken, Greene, Worden, Harrison, & Spielberger, 1987).

Psychosocial variables, such as family and social support, are also widely believed to have an important impact on the ultimate medical and psychological success of the transplant. Christopherson and Lunde (1971) reported that in a sample of cardiac transplantation recipients, open patterns of family communication that supported the decision to undergo transplantation were associated with positive post-transplantation adjustment. Mishel et al. (1987) has suggested that transplantation families go through a process of "redesigning the dream" which requires the family to continually adjust to the changing demands and goals of post-transplantation life. The family's ability to modify and ultimately renew the roles of the transplantation recipient may be related to the recipient's perceived quality of life. Baker, Curbow, and Wingard (1991) studied the relationship between post-bone marrow transplantation role retention and quality of life. Role retention was defined as the degree to which the recipient could perform the family, work, and community roles that they were accustomed to performing. Results indicated that role retention was significantly associated with measures of quality of life including current and future life satisfaction and measures of positive affect. Furthermore, significant relationships were found between negative mood and role

retention. These findings suggest that negative mood affects quality of life by reducing the roles of the transplantation recipient.

Other dimensions of negative affect, such as anxiety and anger, have received significantly less attention from transplantation researchers than depression. This is somewhat surprising given the moderately high correlations between the constructs of depression, anxiety, and anger which have led to suggestions that a single factor of negative affect may underlie these overlapping dimensions (Matthews, 1988). Nonetheless, anxiety has been implicated as an important presentation of distress during critical stages of the transplant process (Kuchler et al., 1991) and may serve as an indicator for psychotherapeutic intervention during these periods. Anxiety has been suggested as a possible hindrance in self-care activities that may indirectly influence quality of life (Conn, Taylor, & Wilman, 1991). However, this hypothesis was not supported in a sample of CABG surgery patients. Similar hypotheses about the self-report of anger have been found in hypertensive patients in which self-report of anger was found to be associated with medication non-compliance (Lee et al., 1992). Nonetheless, anxiety and anger may also serve as a potential obstacles in information-gathering about the transplantation process that requires the patient to engage in emotion-focused coping rather than problem-focused coping (Lazarus & Folkman, 1984). These emotion-focused coping strategies could subsequently leave the recipient unprepared to independently deal with the rigors of compliance with the medical regimen in the post-transplantation stages.

Although negative affect could be seen as potentially problematic for the transplantation patient, alternative views also exist. For example, Rabinowitz and Van Der Spuy (1978) found that the admission of anxiety and hostility were associated with positive adjustment in renal transplantation patients. This data is consistent with the view that patients that exhibit anxiety and hostility may be more actively confronting the exact seriousness of their medical condition and therefore, more efficiently dealing with their feelings and subsequently adapting to their situation. As Beidel (1987) has suggested, anxiety and angry feelings remain to be examined more systematically across the stages of transplantation.

Quality of Life by Proxy

Perceived quality of life may vary by the perspective of the rater. Different raters are interested in sampling different domains of quality of life. For example, the medical professional may be interested in the surgical outcome and restorative function of the replaced organ, while the psychologist may be interested in the person's psychosocial functioning post-transplantation. Patients may be particularly interested in the cosmetic aspects of procedures and changes in the inter-familial relationships or sexual functioning due to a procedure. Still another perspective is available through the eyes of the patient's spouse or significant other who may be interested in such things as degree of independence. Mishel and Murdaugh (1987) have suggested that the impact of transplantation on the family requires significant role change within the relationship between recipient and

the spouse. The role of the spouse and the caregiver has gained increased attention from researchers. Sechrest and Pitz (1987) commented that it was "impossible" to examine fully the issue of quality of life without a simultaneous discussion of a transplant's impact on the recipient's significant others.

The similarity between spouse and patient views has been examined. Gray, Brogan, and Kutner (1985) sampled 50 end-stage renal disease patients' satisfaction and abilities in 13 life areas such as leisure time, working life, sexual functioning, and social life and compared their responses with their spouse's own self-view. Interestingly, the patient and spouse views were congruent on 10 dimensions. Patients and spouses differed on satisfaction with medical care, patient's perception of self care, and satisfaction with feelings about self in that patients reported lower levels on these dimensions. This data suggests that there is a high correspondence between patients and their spouses in perceptions of important life areas. The concerns of spouses of transplantation recipients have also been found to be consistent with one another. For example, Buse and Pieper (1990) studied the perceptions of 30 spouses (26 women & 4 men) after their spouse received a cardiac transplant during the pre- and posttransplantation periods and found that cardiac spouses do not experience a reduction of stress from pre to post-transplantation but rather maintain high levels of stress. More specifically, the central concerns of spouses appeared to be the possible loss of the loved one, life in general, and the need to learn more about the transplant.

The spouse's perspective may be particularly useful, because it is very likely that it is the spouse who spends the most time with the patient, due to the extensive care-giving responsibilities. However, care-giving has been shown to have a significant impact on the caregiver. Caregiver research has recently been flourishing, particularly in the care of the elderly and has focused on two constructs: caregiver burden and caregiver strain. Caregiver burden refers to the more tangible and concrete aspects of providing services, while caregiver strain refers to the subjective appraisal of stress that providing care has on the caregiver (Parks & Pilisuk, 1991). Caregiver strain has received the most research attention and such factors as work interference, personal life impact, and care-recipient impairment have been shown to be significant predictors of reported strain (Scharlach, Sobel, & Roberts, 1991). Women also appear report more caregiver strain, probably because they are more likely to involve themselves in the role of the caregiver (Parks & Pilisuk, 1991). The degree of caregiver strain is thought to be part of the view that a proxy rater would have of the patient.

The issue of rating a patient's quality of life by proxy has begun to draw the attention of researchers because of its potentially rich source of easily attainable data. Magaziner et al. (1988) studied the comparability of 361 elderly hip fracture patients and their spouses interview responses to measures of health and functional status. The results indicated that proxies tended to overestimate patient disability relative to the patients themselves, especially with regard to the capacity to complete activities of daily living. Proxies with the greatest contact with the patient tended to have the

highest agreement with patient responses. However, on measures of functional and health status, proxies tended to report more patient disability than the patient. The authors provided tentative reasons for proxy overestimation such that proxies may want to elicit sympathy and additional help from others or it may be a function of their own over-protectiveness of the patient.

Epstein et al. (1989) found similar results in an adult sample of primary care patients at a university medical center. The researchers asked proxies to respond to measures of functional, emotional and health status, social activity, and satisfaction in the same manner that they thought the patient would. Patient and proxy correlations were highly significant for overall health, functional status, social activity, and emotional health and moderately correlated for satisfaction. Proxies reported lower satisfaction and emotional health than did the patients. Proxies who spent more time per week helping the patient rated the patient as more impaired than did the patient. The authors concluded that proxy responses are not able to inter-mixed with patient response, rather proxy responses represent a different data set that should be examine separately.

Sprangers and Aaronson (1992) provided an overview of the research studies comparing patient and significant other ratings of health status and quality of life. Their review of 13 studies suggested that the level of agreement between patients' self-reports and significant other's ratings was dependent on the concreteness, visibility, and subjectivity of the quality of

life dimensions assessed. The authors found that the less concrete and visible and the more subjective the information, the lower the concordance rates. Ratings of such things as functional status seem to be highly correlated while ratings of psychological distress seem to be correlated moderately or minimally. The authors concluded that there is a tendency for significant others to more negatively rate the quality of life and performance of the patient. Some evidence exists that variables such as proximity of the raters living arrangements (e.g. in the same household), performing a caregiving function, and amount of time devoted to caregiving impact the level of correspondence between significant other and patient ratings.

The central aim of many of the studies in the quality of life by proxy area was to examine the correspondence between patient and spouses in order to replace missing values of patients who either refused or were unable to respond to the measures of the given study. Although this is a worthy goal for research methodology, the present study intended to sample the significant other's perspective for its own sake. This strategy was designed to capitalize on the unique perspective that the significant other holds on the patient's quality of life. The two sets of ratings were assessed for correspondence but no replacement of missing data was performed. Instead, parallel analyses were performed in order to find significant markers for both the patient's and the significant other's ratings of quality of life.

Quality of Life in Cardiac Transplantation

Quality of life measures have been used in the assessment and follow-up care of cardiac transplantation recipients in a variety of studies during the last decade. The following section provides a detailed analysis of the current literature examining quality of life in cardiac transplantation recipients and concludes with a brief summary of critiques and findings from these studies.

Review of studies

Quality of life has been operationalized in a variety of ways. Some studies have examined quality of life by using simple questions about the perceived quality of life in multiple domains of interest. Bunzel, Grundbock, Laczkovics, Holzinger, and Teufelsbauer (1991) surveyed 35 patients (32 male, 3 female) about their postoperative progress and satisfaction on visual analog scales of quality of life. The researchers defined life quality in nine areas: physical, emotional, mental, vocational, and sexual status, financial situation, leisure activities, partnership, and overall life quality. The patients sampled ranged from 13 to 45 months post-transplantation. Results indicated that patients reported increased functioning and satisfaction in all 9 areas with the exception of financial status. However, the authors acknowledged that this methodology allows only for an approximation because of the limitations of retrospective research. More clearly, no pre-transplantation data was available for systematic comparisons. The authors asserted that patient satisfaction with a medical procedure may be the most

important result of a medical procedure and may be highly associated with increased life quality.

Simple quality of life questionnaires have also been combined with health indices in an attempt to predict quality of life by the relative contribution of somatic complaints or symptom distress. Lough, Lindsey, Shinn, and Stotts (1987) developed a symptom checklist designed especially for common symptoms reported by cardiac transplantation recipients. In their study, a list of 29 symptoms was mailed to 100 cardiac recipients with instructions to rate the frequency and emotional distress caused by each symptom on a five-point scale (0 = never have that symptom to 4 = always have that symptom; 0 = not at all upsetting to 4 = extremely upsetting). The sample of returns included 65 men and 10 women. The time since transplantation ranged from 7 months to 14 years. Although medication types were controlled for and some significant differences occurred between medication groups, there were some symptoms that occurred "often" or "always" regardless of medication type. The symptoms that were most common included: changed facial appearance, changed bodily appearance, pain, overeating, fatigue, lack of sleep, and decreased interest in sex. The most common symptoms were not always the most distressing; sexual difficulties and decreased sexual interest were rated as the most distressing. Changes in facial and bodily appearance and mood swings also ranked highly among the most distressing symptoms. The cardiac recipients generally described their quality of life as good to excellent (89%), with 82% reporting good to high levels of satisfaction with their

current quality of life. Perhaps the most significant finding from this study involved the regression analysis that indicated that perceived quality of life was significantly predicted by satisfaction, accounting for 63% of the variance. Symptom frequency and symptom distress accounted for a combined 4% of the variance in quality of life. The authors concluded that while transplantation recipients experience recurring physical symptoms and associated emotional distress, other life factors have greater impact on perceived quality of life. These findings indicates that symptom reports are important because symptoms can be distressing to the recipient. However, the report of symptoms appears to distinct from traditional quality of life measures.

Other researchers have used test batteries designed to tap the various psychosocial dimensions presumed to be important. Jones, Chang, and Esmore et al. (1988) contacted 38 consecutive cardiac transplantation recipients for follow-up psychological and quality of life assessments. Subjects completed the Beck Depression Inventory, the State-Trait Anxiety Inventory, the Campbell Well-Being Scale, and measures of body image, current marital and occupation functioning, and perception of transplantation. Patients were evaluated before transplantation, at discharge, and at the 4-, 8-, and 12-month post-transplantation intervals, but the exact number of patients at each of the follow-up assessments varied. All 38 patients were assessed at their first hospital discharge while 32 were assessed at 4-months, 21 at 8-months, and 14 at 12-months. The initial sample included 32 men and 6 women who were generally middle aged ($\underline{X}$

= 38.8 years old), married (79%) with moderate levels of education ($\underline{X}$ = 10.8 years). Results indicated that patients reported significantly higher levels of depression and state anxiety prior to transplantation compared to post-transplantation. Consistent with the psychological measures, the measures of well-being and body image indicated significant improvements from pre to post-transplantation. In addition, it was found that 64% of the patients had either returned to full-time work or to home duties by the time of the 12-month follow-up.

More recently, Jones, Taylor, Downs, and Spratt (1992) followed-up on 38 consecutive cardiac transplantation recipients from the Jones et al. (1988) study to assess current quality of life. Of the 38 in the initial sample, 27 patients were available and participated (6 patients died, and 5 were unable to be contacted) in a long-term follow-up approximately 4 years post-transplantation. Each patient completed the pre-transplantation battery as well as the Nottingham Health Profile (NHP), which is a measure of pain, physical mobility, sleep, energy, social isolation and emotional reaction. Consistent with the previous study, significant differences were found on measures of depression, anxiety, and well-being between pre and post-transplantation. However, no significant differences were found between any of the follow-up periods. More clearly, the initial gains post-transplantation did not increase significantly at the subsequent time periods. However, it should be noted that the well-being scores at each of the follow-up periods were significantly higher than the general population, suggesting that transplantation recipients may view their lives with more positive

meaning following transplantation than the general population. On the NHP, comparisons of the recipient's scores to a general medical population suggested that the recipients reported less pain, more energy, and less emotional reactions. Overall, these studies by Jones and his colleagues show consistent quality of life and psychological benefits for the cardiac recipient immediately following transplantation longitudinally up to a 4-year follow-up.

Other batteries to examine the psychosocial functioning have been developed by Freeman, Folks, Sokol, and Fahs (1988). These authors evaluated a group of 70 cardiac transplant recipients during the pre-transplantation stage as well as in regular follow-ups post-transplantation (within the first 6 months, again between 6 and 12 months, and annually thereafter). Subjects were administered a Mini-Mental Status Exam (MMSE), the State-Trait Anxiety Inventory, the Zung Depression Scale, and the Psychosocial Adjustment to Illness Scale (PAIS), a measure of the patient's adjustment in 7 domains: health concerns, vocational status, domestic environment, sexual functioning, family, social activity, and psychological distress. The sample included 50 men and 20 women and was 84% Caucasian and 11% African American. The authors presented some general baserates of psychiatric diagnoses and interventions. Pre-transplantation assessments indicated that 26 patients were given Axis I psychiatric diagnoses while 8 were given Axis II diagnoses. Results indicated a significant relationship between an Axis I diagnosis and persistent regrets following surgery. The authors reported that 24 out of the 70 recipients

assessed required a psychological intervention of some kind. The longitudinal comparisons from pre to post-transplantation indicated statistically significant improvements in anxiety, depression, and adjustment. However, no differences were found on the MMSE. Although disease type was not a focus of this study, the researchers noted that more difficulty with adjustment was observed in individuals with acute onset cardiomyopathy, such as that seen in viral cardiomyopathy in which heart failure can occur in less than one year. It is thought that the acute nature of disease onset allows the patient less time to adjust to his/her condition, given that prior to this time the individual may have been relatively disease-free.

Some researchers have utilized the Nottingham Health Profile as an index of quality of life. O'Brien, Banner, Gibson, and Yacoub (1988) implemented the NHP in pre and post-transplantation assessments with 48 heart and lung patients. Their sample included a majority of women (67%) with a mean age of 23.8 years. The NHP was administered by interview at assessment and by questionnaire at the 3, 6, and 12-month periods post-transplantation. The results indicated significant improvements in each of the areas of Part I of the NHP including energy, pain emotional reactions, sleep, social isolation, and physical mobility. Similar significant improvements were found in Part II of the NHP including the domains of occupational, domestic, social, sexual, and recreational (hobbies and holidays). The authors noted that the NHP was particularly useful in

combining both clinical and research applications because it was easily adapted as either a questionnaire or as an interview instrument.

Caine, Sharples, English, and Wallwork (1990) used the NHP to compare within subjects changes over the stages of cardiac transplantation. Patients ($\underline{n}$ = 196) responded to the NHP at regular intervals following acceptance into the transplantation program. All patients completed the NHP immediately after acceptance to the waiting list prior to transplantation, and regularly at 3 month intervals prior to transplantation and throughout the post-transplantation period up to 5 years. No data was provided indicating the number of subjects reporting at each interval. Short-term follow-up results from comparisons of the most recent pre-transplantation reports to the 3-months post-transplantation evaluation indicated significant improvements in all six dimensions for the 122 patients sampled. However, similar to other studies (Jones, Taylor, Downs, & Spratt, 1992), no statistically significant improvements were found in comparisons between the 3-month post transplantation reports and any following post-transplantation reporting period. All post-transplantation reports were within normal limits when compared to a normative sample of adults. The researchers also found that the NHP was a reliable predictor of outcome in terms of length of stay in the hospital and return to work and leisure activity at 3 months post-transplantation.

Because most quality of life research indicates that quality of life does, indeed, increase as a result of cardiac transplantation, a logical step

for researchers would be the attempts to find significant pre-transplantation indices that are predictors of post transplantation quality of life (Shapiro, 1990). Brennan, Davis, Bucholz, Kuhn, and Gray (1987) conducted a pilot study with 11 transplantation recipients that examined pre-transplantation DSM-III diagnoses, the intervening medical course, and quality of life at 9 to 15 months post-transplantation. The authors performed psychiatric evaluations on all patients and diagnosed 3 patients with personality disorders, 3 with depression/anxiety, and 3 with dementia/delirium symptomatology. Medical course was operationalized by the number of days spent in the hospital following the transplant and the number of biopsies performed. It was presumed that the number of biopsies performed during a given period was related to the severity of rejection undergone during that period. The average number of biopsies performed was 10.5 during the first six months, and 3.4 during the second six months. Results showed that patients with more positive quality of life following cardiac transplantation tended to be married, did not carry a diagnosis of a personality disorder before the operation, had a shorter post-transplantation hospital stay, had fewer days of readmission, and underwent fewer biopsies in the year following cardiac transplantation. The authors suggested that there may be some inter-relationship between marital status and personality disorder influencing medical outcome, which in turn influenced quality of life. The authors concluded that compliance to the medical regimen may also be a moderating factor.

Mai, McKenzie, and Kostuk (1990) also studied the role of psychopathology and compliance in a study of the pre to post-transplantation psychosocial and quality of life adjustment of 27 consecutive cardiac transplantation recipients. Subjects responded to the Present State Examination (PSE), a structured psychiatric interview schedule, the Symptoms Checklist (SCL-90), and the General Health Questionnaire (GHQ). In addition, the clinical team rated the patients on a 3-point scale of compliance (good, fair, poor) that was based on the self-report of the patient as to the extent to which he/she had followed medical requirements concerning diet, salt restriction, smoking, exercise and drug and alcohol ingestion. The medical team also completed a non-standardized quality of life measure that assessed current physical activity, employment status, and sexual activity from the medical record. At the pre-transplantation assessment, 14 of the 27 patients received a PSE psychiatric diagnosis, while 5 of the 24 received a PSE diagnosis at the 12 month post-transplantation follow-up. An association was found between the pre-transplantation rating of compliance and psychiatric diagnosis. Pre-operatively, 47% of patients rated as compliant had a psychiatric diagnosis, whereas 100% of the patients rated as having "fair" or "poor" compliance had a psychiatric diagnosis. The authors hypothesized that the presence of psychopathology impairs the capacity of the individual to follow the medical regimen.

Additional psychosocial information was gained from the psychometric assessments that utilized questionnaires. Results from the

SCL-90 indicated highly significant improvements from pre to post-transplantation scores on the Anxiety, Phobic Anxiety, Additional Items, Total Score, and Symptom Distress Index. In contrast, the GHQ did not show statistically significant pre to post-transplantation improvement. However, trends were noted in the expected direction of improvement. Statistically significant improvements were also shown in the areas of physical activity and employment indicating that most patients had returned to a desired level of activity. The sexual activity measure was only able to be compiled for 14 subjects and the data suggested that libido was normal in 8 patients, impaired in 3, and absent in 3. Overall, the authors indicated that patients did increase their quality of life after transplantation because of the significant improvements noted in physical activity, return to work, and resumption of sexual activity.

Packa (1989) contacted 22 cardiac transplantation recipients approximately 6-12 months after transplantation. Each of the subjects completed the McMaster Health Index Questionnaire (MHIQ) and the Cantril Self-Anchoring Scale. Results from the MHIQ indicated that subjects reported "satisfactory" levels of functioning in the physical, social, and emotional domains. The Cantril Self-Anchoring Scale was administered by asking subjects to rate their quality of life on a continuum (0 = worst possible quality of life imaginable and 10 = best possible quality of life imaginable). Subjects were asked to make ratings of their quality of life retrospectively at one-month before transplantation and at time of interview. In addition, subjects were asked to forecast their anticipated quality of life at

5-years post-transplantation. Significant differences were found between the scores at all three time periods such that cardiac transplantation recipients expected a continued progression of improvement over time.

Summary and Conclusions

Before drawing conclusions about findings from the studies reviewed, several caveats are necessary. First, each of the studies generally relies on convenience sampling at the researcher's particular setting. The samples tend to be consecutive patients that are evaluated pre-transplantation and are subsequently deemed as "acceptable" for the transplantation waiting list. Thus, patients are not randomly selected, but rather are purposefully selected based on both medical and psychosocial characteristics. Second, the samples tend to be relatively small in number. Although the number of cardiac transplantation centers is rapidly growing, each center generally does not transplant large numbers of patients and multi-center studies are the exception rather than the rule (Paris, Woodbury, Thompson et al., 1992). Third, great variability in the operationalization of the constructs of interest is evident. The quality of life construct certainly has a wide range of meanings and relatively little consensus can be found about how to measure it best. Fourth, researchers have traditionally relied only on the self-report of the patient of his/her quality of life and have not compared the alternative views of significant others such as the spouse or extended members of the family. Fifth, the timing of assessment and the number of assessments also varies dramatically across studies providing a mosaic of views of quality of

life at different stages and times of post-transplantation. Despite these shortcomings, the critical work related to quality of life post-transplantation continues while each researcher attempts to define or operationalize quality of life according to his/her purposes.

Although it is premature to form conclusive statements about the cardiac transplantation quality of life literature, general trends can be noted. The studies reviewed above suggest that the quality of life of cardiac transplantation recipients increases after undergoing transplantation. The changes are statistically significant from pre- to post-transplantation and are in place within 3-4 months following surgery. Longitudinal repeated comparisons of quality of life after the 3-4 month period are generally not statistically significant, suggesting that most of the significant quality of life change occurs in the period directly following transplantation (Jones, Taylor, Downs, & Spratt, 1992). Additional studies have indicated that reports of anxiety and depression are significantly reduced from pre- to post-transplantation (Jones et al., 1988). Concerns about sexual functioning and appearance appear to be frequently reported post-transplantation (Lough et al., 1987). The return to work rates appear to be promising ranging from 56% to 64% (Shapiro & Kornfeld, 1989), but no systematic predictors have been established (Jones et al., 1988; Paris et al., 1992). Because most quality of life research indicates that quality of life does, indeed, increase as a result of cardiac transplantation, Shapiro (1990) has suggested that research should focus on establishing significant pre-transplantation predictors of post transplantation quality of life.

Previous Research at the University of Florida

The psychological perspective on cardiac transplantation has a relatively strong history at the University of Florida. Cardiac transplantation candidates have routinely been evaluated by the faculty and students of the Department of Clinical and Health Psychology since the commencement of transplantation at Shands Hospital in 1985. Psychologists have been consulted as part of multi-disciplinary teams presumably to make assessments of the candidate's psychosocial situation by sampling the patient's mental status, level of affective distress, substance use/abuse history, medical compliance history, coping style, social support, and knowledge of current illness. In the context of these evaluations, clinical interviews and psychological testing were implemented to aid in the clinical management of patients and a complementary research protocol was established. The evaluations were designed to broadly sample the patient's affect, behavior, and cognition. Accordingly, psychological tests were selected that would best measure the domains of interest. The exact measures for each of these domains have undergone some changes along with the personnel performing the evaluations. Nonetheless, some measures have remained constant and those measures are the focus of the current study. Personality has been assessed using the Minnesota Multiphasic Personality Inventory (MMPI) (Hathaway & McKinley, 1967), which has been called the "most thoroughly researched personality assessment instrument available" (Green, 1985, p. 318). The MMPI is a self-report psychiatric screening measure that provides scores on numerous subscales and allows

for examination of response-style distortions through the use of "validity scales." Intellectual and cognitive status have been examined through the use of the Wechsler Memory Scale (WMS) (Wechsler, 1945) and the two subscales, Vocabulary and Block Design from the Wechsler Adult Intelligence Scale-Revised (WAIS-R).

The clinical practice of routine assessment of cardiac transplantation candidates has lended itself well for data collection for research. For example, Hecker, Norvell, and Hills (1989), while working at the University of Florida, were the first authors in the psychological literature to validate the use of MMPI profiles in the assessment of cardiac transplantation candidates. The authors also established a normative data base for cardiac transplantation candidates on other psychological measures. They performed cluster analyses and found three MMPI profile subtypes that have been replicated (see below, Robinson, Greene, & Geisser, 1993). Cluster 1 ("Neurotic Triad" and/or "High Distress") included patients who were reporting a variety of physical complaints, were significantly anxious and depressed, and admitted to a degree of confusion. Cluster 3 ("Subclinical V-type") also reported significant physical complaints but did not report significant depression or anxiety. Finally, Cluster 2 ("Normal") reported no significant elevations on MMPI scales and were indicative of a fairly well-adjusted group. Caution in interpretation was emphasized by the authors because the analyses included only 64 patients.

More recently, Robinson, Greene, and Geisser (1993) also used cluster analyses to examine MMPI profiles in various medical populations including chronic lower back pain, headache pain, and cardiac transplantation candidates. The cardiac disease population included both the Hecker et al. (1989) sample and the sample that will be used again in the current study. These authors found four clusters in a large sample of cardiac transplantation candidates including the 3 clusters that were originally found by Hecker et al. (1989). The fourth cluster group appeared to form with members of original Cluster 1 that separated into two groups: the "Neurotic Triad" and the "High Distress" groups. It also important to note that the "Normal" group remained composed of subclinical scores on all MMPI scales but showed a near elevation on Scale 9 (Hypomania scale). Although both Hecker et al. (1989) and Robinson et al. (1993) found similar profile groups, the predictive validity and utility of the clusters in the assessment of post-operative functioning remain to be examined.

Longitudinal assessment of the cardiac transplantation candidates has been examined in two investigations. First, a case study has been presented that demonstrated the clinical utility of psychometric testing across the stages of transplantation (Greene, Sears, & Mills, 1993). Second, a repeated measures design was employed to assess cognitive changes immediately post-transplantation (2 weeks) and after one-year. Personality was also assessed at the one year point. Results indicated at post-transplantation that measures of depression were significantly reduced at the post-transplantation period. In addition, a trend was noted for memory

functioning such that recipients tended to increase their ability to perform memory tasks as operationalized by the memory quotient. The repeated measures findings, however, were limited by a somewhat small sample. The post-transplantation sample was reduced partially because of the increasingly difficult task of systematically following-up on each of the recipients. The difficulties have arisen because of the larger numbers of patients being seen for pre-transplantation evaluations as well as the increasing number being transplanted and being hospitalized for shorter periods of time.

The current study stemmed from the practical, clinical, and empirical needs of continuing the work at the University of Florida in the psychological factors of cardiac transplantation. From a practical standpoint, telephone contact as a follow-up method allows for more convenient access to the medical team than consistently presenting for additional clinical visits. Clinically speaking, further information is needed about the long-term quality of life of cardiac recipients. It is our impression that further contact between the recipient and the hospital is desired by the patient for support, but is currently under-served for the multiple-year surviving recipient. The information gained from this study would provide additional data about the long-term adjustment of transplantation recipients. However, the current project goes beyond the work of other studies and attempted to predict the long-term data with the personality and cognitive functioning pre-transplantation. From an empirical standpoint, quality of life is increasingly becoming an important outcome variable that may become a part of health

care planning and policy planning. Information about the pre-transplantation predictors may allow for systematic interventions that could be tailored to affect the quality of life of future recipients.

<u>Overview</u>

The present study was a longitudinal investigation of cardiac transplantation recipients of Shands Hospital at the University of Florida. The purpose of the present study was four-fold: 1) to provide descriptive information about the prevalence of immunosuppressive symptomatology and quality of life of cardiac transplantation recipients, 2) to test the predictive validity of a pre-transplantation psychological assessment battery on the recipient's perceived post-transplantation quality of life, 3) to test the predictive validity of the pre-transplantation psychological assessment battery on the perceived post-transplantation quality of life by spouse/proxy, and 4) to assess the correspondence of the patient and proxy raters on quality of life.

Structured telephone interviews were used to record the recipient's and spouse/proxy's view of the recipient's quality of life. Quality of life was defined as a multi-dimensional construct that included: a symptom report, a satisfaction report, and a health report. The recipient and spouse/proxy responses to these various instruments were then merged by the recipient's medical record number to the recipient's pre-transplantation psychological test results. The pre-transplantation psychological test results (measures of intellectual and cognitive functioning, as well as personality), relevant

medical variables (e.g., ejection fraction), and demographic characteristics served as independent variables in the prediction of two sets of perceptions of post-transplantation quality of life, the recipient's and his/her spouse/proxy's. This compilation of information allowed for the examination of possible pre-transplantation "markers" that were associated with desired post-transplantation quality of life. Correlations and planned comparisons between the recipient and the spouse/proxy perceptions of the recipient's quality of life were calculated to examine the differing perspectives on quality of life.

The current study was designed to closely ally the science and practice of psychology. The pre-transplantation test battery was composed primarily of frequently used clinical instruments. In addition, due to the relative dearth of longitudinal, predictive studies with cardiac transplantation recipients many of the following hypotheses stemmed from clinical experience and the research findings from other organ transplantation recipients.

<u>Hypotheses</u>

1) Descriptive analyses of the indices of quality of life were expected to show that the recipients have good quality of life as reported by both the recipient and spouse/proxies.

2) It was expected that the pre-transplantation personality cluster groups found by Robinson, Greene, and Geisser (1993) would be replicated in this study and form four cluster groups.

3) The pre-transplantation personality cluster groups were expected to be significantly different from one another on the post-transplantation quality of life variables, while controlling for the relevant medical and/or demographic variables.

If significance for personality cluster was secured, planned comparisons were hypothesized as follows:

a) The High Distress group (elevations, in order, on the MMPI subscales of depression, hypochondriasis, and hysteria (scales 2, 1, and 3)) will differ from the other 3 cluster groups and will report the lowest life satisfaction and the lowest general health, mental health, and physical functioning.

b) The Neurotic Triad group (elevations on the MMPI subscales of hypochondriasis, hysteria, and depression (subscales 1, 3, and 2)) will report a high degree of disease symptoms similar to the Subclinical V group. However, the Neurotic Triad group will have better general health, mental health, physical functioning, and satisfaction than the High Distress group.

c) The Subclinical V group (elevations on MMPI subscales of hysteria, hypochondriasis, and depression (subscales 3, 1, and 2)) will report a high degree of disease symptoms and the low general health. However, this group will have similar life satisfaction, mental health, and physical functioning to the Neurotic Triad group.

d)   The Normal group (near elevation on the MMPI Mania subscale (Scale 9) is expected to report the highest physical functioning, mental health, and general health.

4) Similar predictions were made for the proxy ratings of the patient's quality of life.

5) In regard to patient-proxy correspondence on the quality of life indices, it was expected that all measures would be significantly related. However, significant differences were hypothesized on the measures regarding role limitations due to physical and mental problems. It was expected that proxy raters would rate the recipient as significantly more limited than the recipient rates himself\herself. In addition, significant differences were expected on Mental Health, such that recipients would rate their functioning higher than spouse/proxies would rate the recipient's functioning.

METHOD

Subjects

The sample included 83 cardiac transplantation recipients and 67 spouses/significant others from Shands Hospital at the University of Florida. The majority of the recipients were male (84%), Caucasian (93%), and married (83%). The mean age of the recipient sample was 55.9 years (sd = 8.8). The most common diagnosis for the recipients was ischemic cardiomyopathy (65%) and idiopathic/viral cardiomyopathy (31%). Of the spouses/proxies, 72% were female and 75% were spouses. The mean age of the spouse/proxies was 54.7 years. Table 2 provides sample frequencies on demographic variables. Additional descriptives regarding the medical variables are presented in the Results section.

Subjects participated on a voluntarily basis and received no compensation for their involvement. Informed consent procedures as reviewed by the Institutional Review Board (IRB) at the University of Florida Health Science Center were utilized. The inclusion criteria for participation in this study were that all subjects were at least 3 months post-transplantation and had completed a routine pre-transplantation psychological assessment independent from their participation in this study. Attempts were made to

Table 2
Demographic Data

Variable	Recipient		Proxy/Spouse	
	n	%	n	%
Gender				
Males	70	84.3	7	10.4
Females	13	15.7	60	89.6
Race				
Caucasian	77	92.8	60	92.3
African-American	5	6.0	4	6.2
Hispanic	1	1.2	1	1.5
Marital Status				
Single	6	7.2	10	15.6
Married	69	83.1	54	84.4
Divorced	6	7.2	0	0.0
Widowed	2	2.4	0	0.0
Employment Status				
Full-time	17	20.5	30	44.8
Part-time	5	6.0	4	6.0
Retired	28	33.7	19	28.4
Unemployed	6	7.2	12	17.9
Disabled	27	32.5	2	3.0
Education in Years				
8-11	7	8.6	9	13.4
12 (H.S. Diploma)	32	38.6	29	43.3
13-16	29	34.9	22	32.8
17-21	13	15.6	6	11.1
Missing	2	2.4	1	1.4
Diagnosis				
Ischemic	53	65.4		
Idiopathic/ Viral	25	30.9		
Congenital	3	3.7		
Missing	2	1.2		

contact all of the potential 108 recipients by telephone. The return rates were approximately 78% for the recipients and 81% for the proxy raters.

These return rates compare favorably to studies with similar methodologies (e.g., Magaziner et al., 1988: 49% for patients and 86% for proxy raters). The majority of missing subjects ($\underline{n}$ = 12) were unable to be reached after repeated attempts. Other reasons for not participating included: refusal to participate ($\underline{n}$ = 6), death during study time period ($\underline{n}$ = 3), no valid phone number ($\underline{n}$ = 2), and physically unable to participate due to hearing loss ($\underline{n}$ = 1). The participation of spouse/proxies was solicited only after securing data and permission from the recipient. Reasons for missing data in the spouse/proxy group included: single/no proxy ($\underline{n}$ = 9), ineligible due to assisting recipient in responding ($\underline{n}$ = 2), spouse/proxy deceased ($\underline{n}$ = 2), refusal ($\underline{n}$ = 2), and unable to reach after repeated attempts ($\underline{n}$ = 1).

Procedures

Following project approval by the Institutional Review Board, a master list of cardiac transplantation recipients was obtained from the Division of Cardiothoracic Surgery at the University of Florida/Shands Hospital. Potential subjects were cross-checked by clinical research assistants in the Psychology Clinic to ensure that psychological test results from the recipient's pre-transplantation evaluation were available. After this confirmation, letters from the principal investigator and the Director of the Cardiac Transplantation Program were sent to the cardiac transplant recipients describing the rationale for the study and seeking the participation

of the recipient and his/her spouse/proxy. Subjects were then contacted by phone and semi-structured quality of life interviews were conducted by research assistants. Data sheets containing the respondents' ratings were completed by the interviewer during the phone interview. Confidentiality was maintained by using only the patient's project subject number on the data sheets in the data set. Subject numbers were later linked to medical record number for the purpose of merging pre-transplantation data. All other identifying information was deleted.

Telephone interviews consisted of two interviews, one interview focused on the perceptions of the transplant recipient and one focused on the perceptions of the recipient's spouse/proxy. The interviews were performed consecutively with recipient typically responding to interview questions first. In most cases, the interviews were performed on the same day, during the same phone call. The interviews were conducted primarily by trained undergraduate research assistants and lasted 30 minutes per respondent. The training for the interviewers consisted of approximately 20 hours of didactic presentations of significant issues in cardiac transplantation, case presentations, literature review, and role playing.

Measures

Pre-transplantation assessment battery. Intellectual screening was performed using the Vocabulary and Block Design subtests of the Wechsler Adult Intelligence Scale-Revised (WAIS-R). The raw scores obtained were converted to Scaled Scores in which a Scaled Score of 10 is average and

the standard deviation is 3. Previous research has found that these two subscales have the highest correlations with the Full Scale I.Q. ($\underline{r}$ = .89; Ryan, Larsen, & Prifiteria, 1983). Vocabulary and Block Design are thought to tap the abilities of verbal comprehension and perceptual organization, respectively. Evidence exists that these scales can be summed to form an extrapolated intelligence quotient (Silverstein, 1982).

The Wechsler Memory Scale (WMS) was given to assess the various aspects of memory functioning. The WMS consists of seven subtests including: Personal and Current Information (PI) and Orientation (OR) (e.g., questions related to ability to recall current information about patient's age, location, and government officials), Mental Control (e.g., counting by 3's), Logical Memory (e.g., memory of a story), Memory Span (e.g., digit recall forwards and backwards), Visual Reproduction (e.g., memory for figures), Associate Learning (e.g., memory for paired associates). The patient's raw scores on these tests are summed and an age correction factor is added to obtain a summary score called the Memory Quotient (MQ). Spreen and Strauss (1991) have summarized the criticisms of the WMS. They list the following limitations: 1) inadequate norms, 2) the MQ score does not differentiate between the various facets of memory, 3) over-reliance on immediate recall and no long-term memory sampling, 4) lack of control for visuoperceptive and visuomotor abilities in so=called tests of visual memory, 5) imprecise scoring criteria, 6) overemphasis on verbal tasks, 7) orientation and mental control not genuine measures of memory. Despite

these criticisms, the WMS has been one of the most used measures of memory in clinical practice.

Personality was assessed using the Minnesota Multiphasic Personality Inventory (MMPI). The MMPI allows for the multi-dimensional assessment of personality with related sampling of response-style distortions. The MMPI was empirically derived which refers to the ability of the items to discriminate between criterion groups such as normals and psychiatrically diagnosed persons. In the current study, the 10 clinical scales, the four validity scales, and four supplementary scales were used. The scales are as follows: Scale 1 = Hypochondriasis, Scale 2 = Depression, Scale 3 = Hysteria, Scale 4 = Psychopathic Deviate, Scale 5 = Masculinity/Femininity, Scale 6 = Paranoia, Scale 7 = Psychasthenia, Scale 8 = Schizophrenia, Scale 9 = Mania, Scale 10 = Social Introversion. The validity scales include: L = Lie Scale, F = Infrequency scale, K = Correction scale, and ? = Question scale. The MMPI has been widely used despite some limitations. Green (1985) reviewed the psychometric information related to the MMPI and found that the reliabilities were generally acceptable with 3-4 day test-retest reliability ranging from .56 to .88, with the majority in the low .80s. Dahlstrom, Welsh, and Dahlstrom (1972) report extensively on the MMPI's validity information.

Negative affect was assessed by the State-Trait Anxiety Inventory (STAI; (Spielberger, Gorsuch, & Lushene, 1970), the State-Trait Anger Expression Inventory (STAXI; Spielberger, 1984), and the Beck Depression

Inventory (BDI; Beck & Beamesderfer, 1974). Each of these measures are among the most widely used to measure their respective constructs.

The STAI is a 40-item questionnaire developed to measure two distinct components of the concept of anxiety. State anxiety is defined as anxiety which a person experiences in response to certain, specific conditions. In contrast, trait anxiety refers to a relatively enduring personality characteristic, specifically, anxiety proneness. The internal reliability of both the state and trait anxiety has been to shown to be uniformly high across samples of adults ranging from .89 to .96. Test-retest validity for the trait anxiety scale for college students over 104 days was .73 for males and .77 for females. Concurrent validity between the STAI and the IPAT Anxiety Scale and the Taylor Manifest Anxiety Scale ranged from .83 to .73 (Spielberger, 1984).

The STAXI is a 44-item, self-report questionnaire designed to measure the experience, control, and mode of expression of anger (Spielberger, 1988). Our analyses focused only on the state and trait anger subscales. The State Anger subscale measures the intensity of angry feelings at a particular time. The Trait Anger subscale provides a measure of individual differences in the disposition to experience anger. The STAXI has excellent psychometric characteristics including test-retest reliability ranging from .71 to .93 in college populations and concurrent validity with other hostility measures.

The BDI is a 21-item questionnaire that measures the intensity of depression-related phenomena such as mood, pessimism, sense of failure guilt, suicidal ideation, etc. Beck, Steer, and Garbin (1988) meta-analyzed the BDI's internal consistency and found a coefficient alpha of .86 for psychiatric patients and .81 for non-psychiatric subjects. Concurrent validity studies yielded a mean correlation with the Hamilton Psychiatric Rating Scale for Depression of .72.

The psychological assessment battery is a part of a comprehensive medical evaluation performed on each transplantation candidate. The different medical indices that were selected for this study are thought to be sensitive to the various aspects of the cardiac transplantation medical presentation. Many of these parameters are particular foci of the transplantation review board decisions. For example, ejection fraction, the global index of the extent of ventricular fiber shortening, is a good measure of the ability of the heart to perform its duty of circulating oxygenated blood to the body. Disease duration was determined by an archival record review that found the length of time between the patient's recollection of first cardiac event and eventual transplantation as measured by months. Diagnostic type was restricted to three different diagnoses including: ischemic and viral cardiomyopathy and congenital disorders. Concomitant disease information was obtained from both medical record review and interview to assess other illnesses that may be contributing to reductions in the recipient's quality of life. Surgical and hospital-related complications (e.g., infections) were assessed using the length of hospital stay between

transplantation and first discharge. Finally, time since transplantation was computed from the number of months between transplantation and the quality of life interview.

Post-transplantation Assessment Battery. Quality of life was operationalized in our study as a multi-dimensional construct that included: symptom report, satisfaction report, and health reports. The questionnaire items are presented in the Appendix.

Symptom report. Because cardiac transplantation is expected to reduce cardiac symptomatology, symptom report was operationalized by the Transplant Symptom Frequency and Distress Scale that was designed for use with cardiac transplantation patients taking immunosuppression drugs (Lough et al., 1987). The scale samples responses to the frequency of 29 symptoms using a 0-4 rating (0 = never have symptom and 4 = always have symptom). In addition, for each symptom that the recipient or proxy acknowledges, they were asked, "Is this a problem for you?" It also is important to note that this question is the only question that was asked differently to the recipient and to the proxy/spouse. Specifically, we were interested in what symptoms were problematic for the recipient but not the spouse and vice versa.

The Transplant Frequency Scale demonstrated an alpha coefficient of .70 in previous work by Lough et al. (1987). This scale resulted in a Symptom Frequency score and a Problem Total score that were used in all analyses. The Symptom Frequency index was formed by computing the

subject's reports of symptoms that occur "sometimes, often, or always."
Symptoms that occur with this frequency were given a value of "1" and
symptoms that occur "never or rarely" were given a "0" for that symptom.

Satisfaction report. The Satisfaction with Life Scale (SWLS)
developed by Diener et al. (1985) is 5-item scale designed to assess
satisfaction with the respondent's life as a whole. The items of the scale
are global rather than specific in nature which allows respondents to weight
domains of their lives in terms of their own values. Pavot and Diener (1993)
detail the psychometric validation of the instrument. Diener et al. (1985)
reported a coefficient alpha of .87 for the scale, and a two-month test-retest
stability coefficient of .82. In a four-year test-retest interval, the SWLS had
a .54 reliability coefficient (Diener, Magnus, & Fujita, 1991). The construct
validity of the SWLS has also been examined in relation to both self-report
and external criteria of measures of subjective well being and life
satisfaction. Pavot and Diener (1993) cite numerous articles that have
generally found that the SWLS is negatively correlated with measures of
distress and positively correlated with measures of positive affect. The
correlations between the SWLS and interviewer ratings have been positive,
ranging from .43 to .66. Additional research found that personal informant
ratings ranged from .28 to .58.

Health Report. The recipient's health-related quality of life was
assessed by the Short Form-36 (SF-36) that was both rationally and
empirically developed as part of the Medical Outcomes Study (Ware et al.,
1994). The SF-36 assesses 8 domains of health functioning including:

physical functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, bodily pain, mental health, vitality, and general health perceptions. Descriptions of each of the health domains and number of items are included below.

1) Physical functioning (10 items) - refers to the extent that health limits physical activities such as self-care, walking, climbing stairs, bending, lifting, and moderate to vigorous activities. The physical functioning measure is essentially equivalent to a functional status measure.

2) Role functioning due to physical problems (4 items) - measures the extent to which physical health interferes with work or other daily activities, including such things as accomplishing less than desired or limitations in type of activities.

3) Role limitations due to emotional problems (3 items) - assesses the extent to which emotional problems interfere with work or other daily activities, including decreased productivity or quality of time spent on activities.

4) Social functioning (2 items) - refers to the extent to which physical health or emotional problems interferes with normal social activities.

5) Bodily pain (2 items) - measures the intensity of pain and effect of pain on normal work.

6) Mental health (5 items) - assesses general mental health including depression, anxiety, behavioral-emotional control, and positive affect.

7) Vitality (4 items) - samples the extent of feelings of energy versus feelings of fatigue.

8) General health perceptions (5 items) - measures personal evaluation of health, health outlook, and perceived resiliency to illness. A final single-item question examines the perceived changes in health from one year ago in comparison to current health.

Despite having only a few items on each scale, the internal reliabilities of the scales range from .77 (Social functioning) to .92 (Physical functioning) in a sample of 3, 053 adults (Stewart, Sherbourne, Hays, Wells, Nelson, Kamberg et al., 1992). The items and scales of the SF-36 are scored so that a higher score indicates a better health state.

The SF-36 manual (Ware et al., 1994) provides a prescribed strategy for handling missing data with SF-36 items. The authors strongly suggest that missing items should be replaced by the average score on the other items of the scale, provided a majority of items were answered on the scale. This method was used manually to replace individual items in the event of a missing item.

RESULTS

Psychological variables. The various indices of pre-transplantation psychological functioning were examined in two ways. First, descriptive statistics of the entire pre-transplantation assessment sample (n = 298) were examined for each of the psychological variables of interest. Second, the indices of pre-transplantation psychological functioning were examined in the recipient group surveyed in our study. The descriptives for these two samples are available in Table 3.

The group means were tested to determine if there were any significant differences between the candidate and recipient groups. Families of comparisons were created and Bonferroni correction procedures were implemented. The families included cognitive (3 comparisons), affective (5 comparisons), and personality functioning (13 comparisons). Results indicated significant differences on the Vocabulary subscale of the WAIS-R [t (1, 165) = -2.47, p < .01] and on the Memory Quotient [t (1, 130) = -2.74, p < .01], such that recipients were found to have significantly greater scores on both measures. Results from tests of the affective measures found that Trait Anxiety was significantly different [t (1, 83) = 2.41, p < .01], such that the recipient group reported less Trait Anxiety at the pre-transplantation assessment. In addition, the groups differed on State Anger

Table 3

Pre-Transplantation Intellectual and Cognitive Functioning Means

	Candidates			Recipients		
Variable	n	M	s	n	M	s
Cognitive Functioning						
Vocabulary*	202	9.53	3.03	79	10.43	2.59
Block Design	195	7.75	2.68	78	8.29	2.48
Memory Quotient*	208	105.13	18.18	70	111.52	16.41
Affective Functioning						
State Anger*	117	11.89	3.77	48	10.83	1.84
Trait Anger	117	16.12	4.59	48	15.31	4.47
State Anxiety	119	39.02	10.80	44	36.52	13.12
Trait Anxiety*	117	37.52	9.46	43	33.77	8.44
Depression	205	11.43	6.90	70	11.14	6.38

* $p < .01$

[t (1, 158) = 2.41, p < .01] with the recipients reporting significantly less anger. In the personality domain, only the F scale of the MMPI was significantly different [t (1, 224) = 3.22, p < .001], such that the recipients scored significantly lower. Table 4 provides the means tested in these analyses.

Medical variables. The results from descriptive analyses with the medical variables found that the sample at the pre-transplantation evaluation was demonstrating severe cardiac dysfunction. The average ejection fraction for the sample was 17.03 (s = 5.61) and the average disease duration ranged from 3 months to 660 months (M = 133.8 months, s = 114.5). Our index of post-surgical complications was the number of hospitalization days following transplantation. The post-hospitalization period was also variable ranging from 10 to 53 days with an average 20.5 days (s = 8.1). Finally, the mean time since transplantation to the date of our contact was 36 months (s = 25.3) with a range of 4-100 months.

Post-Transplantation Quality of Life Measures

Symptom report. According to the recipients, they experienced an average of approximately 10 symptoms. The most common symptom reported was fatigue with 71% of the recipients reporting that they were at least sometimes fatigued. Other symptoms that were most prevalent included: excessive hair growth (67.5%), poor concentration (49.4%), changed bodily appearance (49.4%), bruises (48.8%), fragile skin (48.2%), mood swings (46.3%), and lack of sleep (45.8%). Figure 1 displays the

complete set of symptom reports. Consistent with the most common symptom, the most problematic symptom was fatigue (40.2%). However, the symptom that was reported by the recipients as the second most problematic was difficulty concentrating (29%). Other problematic symptoms endorsed by the recipients included: fragile skin (26.5%), impotence (25.7%), pain (25.3%), changed bodily appearance (24.1%), and swollen ankles (22.9%). Depression was reported by 33.7% and rated as problematic by 20.5% of the sample. Figure 2 displays the prevalence of perceived problems with each symptom.

A slightly different picture of the most common symptoms experienced by the recipients was provided by the spouse/proxies. The spouse/proxies indicated that excessive hair growth was the symptom experienced at least some of the time by the largest number of recipients (74.6%). Fatigue was the second most common symptom as viewed by the spouse/proxies (67.2%), followed by bruises (58.2%), mood swings (56.7%), and lack of sleep (56.3%). Depression was reported as a common symptom for 40.3% of the recipients, as perceived by their spouse/proxies. Figure 3 displays the complete set of symptom reports by the spouse/proxies.

The Problem Total from the spouse/proxy ratings involved sampling ymptoms that are a source of problems for the spouse/proxy. According to the spouse/proxies, the recipient symptom most problematic for them was

Table 4

MMPI Means of Candidates and Recipients

Variable	Candidates		Recipients	
	$\underline{M}$	$\underline{s}$	$\underline{M}$	$\underline{s}$
Personality Functioning (MMPI)				
L	52.26	8.46	52.20	8.30
F*	57.27	9.58	54.22	6.22
K	55.99	9.13	57.90	8.59
1	71.77	11.36	73.17	11.13
2	69.22	11.47	71.79	12.97
3	70.09	9.64	71.18	9.42
4	60.35	9.89	59.29	9.64
5	56.44	9.83	56.05	9.17
6	55.90	9.19	54.96	8.24
7	59.06	9.53	59.49	9.90
8	59.21	10.59	57.87	9.91
9	57.56	11.04	55.61	9.25
10	52.03	8.56	49.72	8.26

[a]$\underline{n}$ = 216. [b]$\underline{n}$ = 82.

* $\underline{p}$ < .01

Figure 1

<u>Symptom Frequencies: Recipient Report</u>

Key:

1 =	Mood swings	16 = Diarrhea
2 =	Lack of sleep	17 = Nausea
3 =	Varicose veins	18 = Taste sensitivity
4 =	Depression	19 = Swollen ankles
5 =	Bad breath	20 = Tremors
6 =	Fatigue	21 = Impotence
7 =	Breathing difficulties	22 = Menstruation
8 =	Changed facial appearance	23 = Bruises
9 =	Changed bodily appearance	24 = Headaches
10 =	Excessive hair growth	25 = Poor concentration
11 =	Acne	26 = Fever
12 =	Fragile skin	27 = Poor vision
13 =	Pain	28 = Heart palpitations
14 =	Overeating	29 = Decreased sexual interest
15 =	Poor appetite	

Percentage Reported

Figure 2

Symptom Frequencies: Spouse/Proxy Report

Key:

1 =	Mood swings	16 = Diarrhea
2 =	Lack of sleep	17 = Nausea
3 =	Varicose veins	18 = Taste sensitivity
4 =	Depression	19 = Swollen ankles
5 =	Bad breath	20 = Tremors
6 =	Fatigue	21 = Impotence
7 =	Breathing difficulties	22 = Menstruation
8 =	Changed facial appearance	23 = Bruises
9 =	Changed bodily appearance	24 = Headaches
10 =	Excessive hair growth	25 = Poor concentration
11 =	Acne	26 = Fever
12 =	Fragile skin	27 = Poor vision
13 =	Pain	28 = Heart palpitations
14 =	Overeating	29 = Decreased sexual interest
15 =	Poor appetite	

Figure 3

Problem Totals: Recipient Report

Key:

1	=	Mood swings		16	=	Diarrhea
2	=	Lack of sleep		17	=	Nausea
3	=	Varicose veins		18	=	Taste sensitivity
4	=	Depression		19	=	Swollen ankles
5	=	Bad breath		20	=	Tremors
6	=	Fatigue		21	=	Impotence
7	=	Breathing difficulties		22	=	Menstruation
8	=	Changed facial appearance		23	=	Bruises
9	=	Changed bodily appearance		24	=	Headaches
10	=	Excessive hair growth		25	=	Poor concentration
11	=	Acne		26	=	Fever
12	=	Fragile skin		27	=	Poor vision
13	=	Pain		28	=	Heart palpitations
14	=	Overeating		29	=	Decreased sexual interest
15	=	Poor appetite				

Percentage Reported

Symptom

■ Recipient

Figure 4

Problem Totals: Spouse/Proxy Report

Key:

1 =	Mood swings	16 =	Diarrhea
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4 =	Depression	19 =	Swollen ankles
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6 =	Fatigue	21 =	Impotence
7 =	Breathing difficulties	22 =	Menstruation
8 =	Changed facial appearance	23 =	Bruises
9 =	Changed bodily appearance	24 =	Headaches
10 =	Excessive hair growth	25 =	Poor concentration
11 =	Acne	26 =	Fever
12 =	Fragile skin	27 =	Poor vision
13 =	Pain	28 =	Heart palpitations
14 =	Overeating	29 =	Decreased sexual interest
15 =	Poor appetite		

Percentage Reported

mood swings (31.5%), followed by impotence (24.4%), changed bodily appearance (24.2%), and decreased sexual interest (22.9%). Depression was noted as problematic by 20.4% of the spouses. Figure 4 provides a graphic representation of both the recipient and spouse/proxy symptom reports.

Satisfaction report. The scores on the SWLS obtained from recipients indicated that they feel a high degree of satisfaction with life (M = 23.67, s = 7.35) that is commensurate with a normative sample of healthy, older adults (M = 25.2, s = 6.7, n = 69; Pavot & Diener, 1993). Similarly, the proxy/spouses reported that they believed that the recipients had a high degree of Life Satisfaction (M = 23.94, s = 7.19).

Health report. The SF-36 scores obtained from the recipients indicated that their reported Physical Functioning, Mental Health, and General Health are within normal limits. Compared to a general United States sample of men and women ages 55-65 (Ware, 1993), these three health indices would place the study sample between the 25th and 50th percentile. Similar scores were found in examining the spouse/proxy reports such that Physical Functioning, Mental Health, and General Health scores were within normal limits, as compared to a general U.S. same age sample. Table 5 provides a full report of both recipient and proxy/spouse scores for each of the SF-36 subscales.

Correlations for Inclusion/Exclusion

Pearson's correlational coefficients were computed to assess the relationships between the full array of potential independent variables representing the medical, demographic, and psychological domains and each of the quality of life variables from the recipient and spouse/proxy raters. Because of the large number of correlations computed, no attempt to systematically interpret each of the correlations was attempted. Instead, the correlations were used to reduce the potential number of covariates by using an inclusion criteria that involved a correlational coefficient with a significance level of $p < .01$. The significant correlations will be reported below.

The demographic correlations were somewhat tenuous because the categories had to be collapsed to form cells with a sufficient size to perform meaningful correlations with the outcome measures. For example, race was collapsed into Caucasian and non-Caucasian. Similarly, marital status was collapsed into married and non-married. Finally, employment was converted to working (full or part-time) and non-working (retired, unemployed, medically disabled). Despite our attempts to sufficiently test for potential relationships, no significant correlations (Pearsons or biserial) were found between the demographic variables and any of the outcome measures from either the recipient or spouse/proxy raters.

The medical variables including days of post-transplantation hospitalization, ejection fraction, time since transplantation, diagnostic type

Table 5

Quality of Life Grand Means

Variable	Recipient			Proxy/Spouse		
	n	M	s	n	M	s
Symptom Report						
Problem Total	77	4.57	4.22	50	3.98	4.04
Frequency	77	9.78	5.22	42	10.74	5.17
Satisfaction Report (SWLS)						
Life	83	23.67	7.35	66	23.94	7.19
Health Report (SF-36)						
Physical Function	83	72.83	23.60	67	67.46	27.98
Role-Physical	83	64.76	38.46	67	58.58	42.76
Role-Emotional	82	86.18	30.52	66	79.29	37.33
Social	83	78.46	25.10	66	74.62	31.77
Mental Health	83	72.63	19.61	66	67.33	21.14
Vitality	83	53.01	24.93	67	52.09	23.81
General Health	83	61.75	24.33	67	58.63	28.99

(ischemic cardiomyopathy and viral/idiopathic cardiomyopathy), and disease duration fared somewhat better in establishing relatively strong correlations with the outcome measures. For example, days of post-transplantation hospitalization was significantly correlated with both the recipient and spouse/proxy rater's scores for General Health (r = -.31, p < .01 and r = -.28, p < .01, respectively). Time since transplantation was also correlated with the recipient and spouse/proxy rater's scores for General Health scores (r = -.27, p < .01; r = -.35, p < .01), respectively. Time since transplantation was also found to be related to the spouse/proxy reports of Physical Functioning (r = -.34, p < .01).

The psychological assessment battery was also subjected to correlational analyses. The variables included in this analysis were: trait anger, trait anxiety, the Wechsler Memory Scale subscales, and the WAIS-R subscales of Vocabulary and Block Design. Trait Anxiety was also found to be correlated with both Symptom Frequency (r = .49, p < .01) and negatively correlated with Mental Health (r = -.49, p < .01). Mental health was also highly correlated with the Beck Depression Inventory (r = -.31, p < .01) suggesting that the mental health index taps mixed emotional features. In sum, the variables that emerge from the correlational analyses that will be included as covariates in the MANCOVA analyses include: the medical variables of time since transplantation and post-transplantation hospitalization time and no demographic variables.

Cluster Analyses

The scores from the MMPI for the full sample of cardiac transplantation candidates were subjected to cluster analyses for the purpose of defining homogeneous groups of candidates with similar scores across the subscales of the MMPI. This strategy was intended to replicate the cardiac transplantation candidate profiles already demonstrated by Robinson, Greene, and Geisser (1993) with a subsample (n = 160) of the current population (n = 298). The Ward method of clustering was utilized because it attempts to minimize the variance within groups and maximize the between group variance. Four groups were specified. The results from this analyses indicated that the larger sample provided generally similar profiles to Robinson et al. (1993) with some notable differences on specific subscales. Cluster 1 (n = 85) was identified as the "Subclinical V-type" such that the highest scale scores were on scale 1 and 3 and scale 2 slightly lower forming a "V" shape when plotted. Cluster 2 (n = 85) was identified as the "Normal" group with no significant elevations on any MMPI subscale. This cluster differed slightly from the Robinson et al. (1993) "Normal" group in that scale 9 was significantly lower than their finding in which this group had a near elevation for scale 9. Cluster 3 (n = 110) was identified as the "Neurotic Triad" group. This cluster group is marked by significant clinical elevations on scales 1, 2, and 3, suggesting affective distress. Finally, Cluster 4 (n = 17) was given a new label, the "Distressed/Confused" group, with significant elevations on all of the clinical scales except scale 5 and 10 and the F scale. This group was not described as the "High Distress" group

consistent with Robinson et al. (1993) labels because there were more clinical elevations in this group after our analysis. Of particular importance was a clinical elevation on scale 8 suggesting mental confusion or unusual sensory experiences consistent with psychotic symptomatology and/or functioning. Figure 5 provides a graphic representation of these cluster groups.

With cluster group membership having been assigned to all transplantation candidates, we sought to examine the frequencies of each cluster among our sample of recipients. This analysis showed that the frequencies for 3 of 4 of the groups was consistent with the larger sample as shown here: Cluster 1 ($\underline{n}$ = 24; 29.3%), Cluster 2 ($\underline{n}$ = 22; 26.8%), and Cluster 3 ($\underline{n}$ = 35; 42.7%). However, Cluster 4 clearly was not well-represented ($\underline{n}$ = 1; 1.2%). Our medical record review of the full roster of recipients including those recipients who did not participate in our study showed that only 1 recipient who was classified in Cluster 4 is still being followed by the Department of Cardiology. The minimal sample size necessary for additional statistical analyses necessitated the omission of Cluster 4 from future analyses. The resulting clusters are shown in Figure 6.

A primary purpose of this study was to examine possible differences between cluster groups on quality of life variables. Multivariate Analyses of Covariance (MANCOVA) were used to test for differences between groups. The covariates (time since transplantation and post-transplantation hospitalization time) were used due to the significant correlations that were

Figure 5

Cardiac Transplantation Candidate MMPI Cluster Groups: Four
Group Solution

Key:

L   = Lie Scale
F   = Infrequency scale
K   = Correction scale
Hs = Hypochondriasis
D   = Depression
Hy = Hysteria
Pd = Psychopathic Deviate
Mf = Masculinity/Femininity
Pa = Paranoia
Ps = Psychasthenia
Sc = Schizophrenia
Ma = Mania
Si = Social Introversion
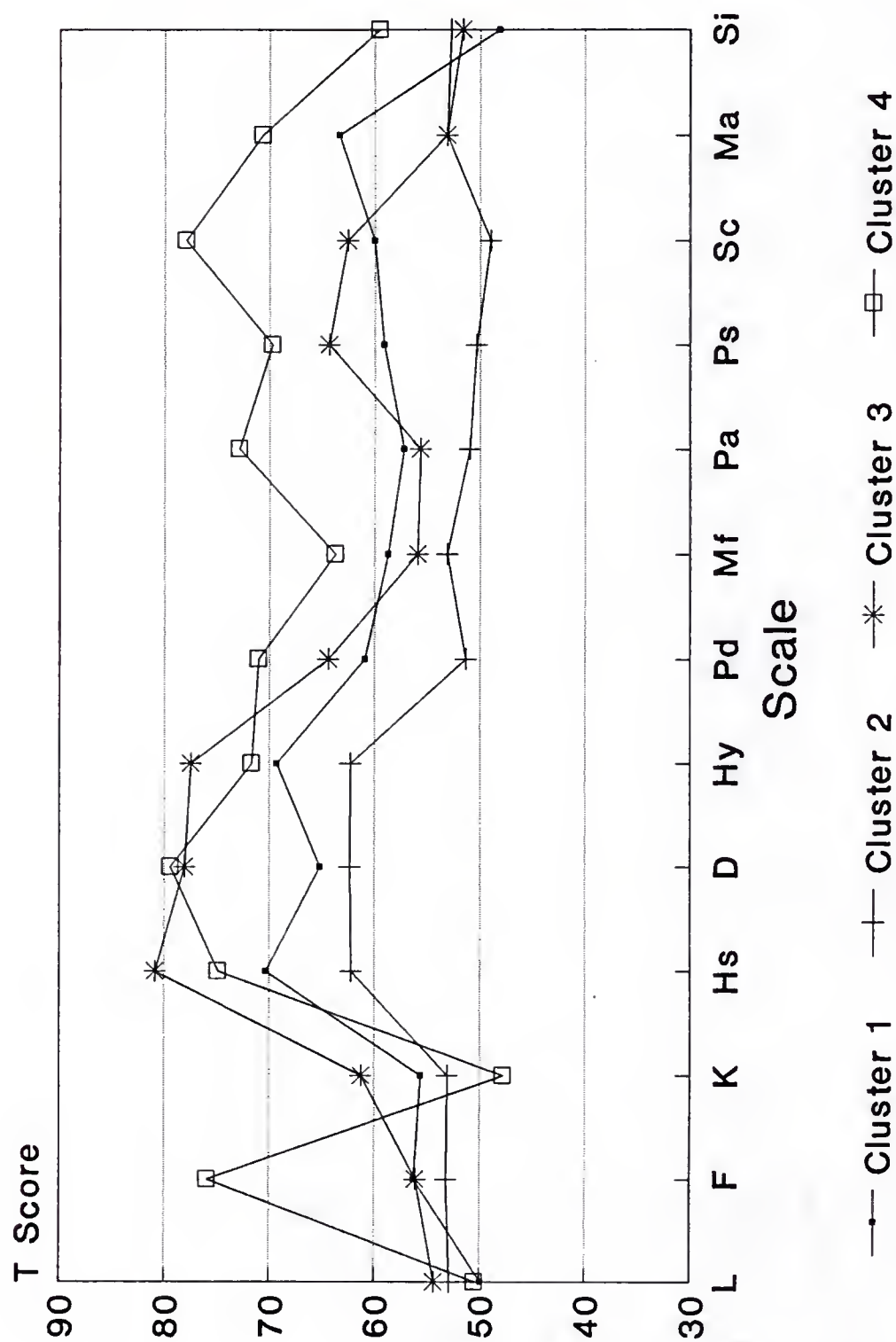
found in the analyses reported above. Two families of dependent variables were used for these analyses: recipient ratings and spouse/proxy ratings. Specifically, 6 tests of cluster differences were performed for both families using the Symptom Frequency, Problem Total, Satisfaction Report, Physical Functioning, Mental Health, and General Health as the dependent variables. The means for each of the cluster groups on the quality of life measures are presented in Table 6.

The family of recipient ratings were examined first. For the Symptom Frequency measure, MANCOVA procedures found no significant differences between cluster groups [F (2, 68) = 1.47, p > .05]. On the second analysis for the Problem Total variable, no significant differences between cluster groups were found [F (2, 68) = .87, p > .05]. The Satisfaction Report was tested next for cluster group differences. However, no significant differences were found [F (2, 74) = .28, p > .05].

The other three MANCOVA procedures using the Health Report found no significant differences for the clusters groups on Physical Functioning [F (2, 74) = .93, p > .05], Mental Health [F (2, 74) = .29, p > .05], or General Health [F (2, 74) = .23, p > .05]. However, post-transplantation hospitalization time (p < .05) was a significant covariate for Mental Health, such that increased post-transplantation hospitalization was associated with decreased mental health functioning. The covariates in the other comparisons were found to be non-significant. Taken together, these analyses suggest that MMPI cluster membership in one of three groups

Figure 6

Cardiac Transplantation Candidate MMPI Cluster Groups: Three
Group Solution

Key:
L =   Lie Scale
F =   Infrequency scale
K =   Correction scale
Hs = Hypochondriasis
D =   Depression
Hy = Hysteria
Pd = Psychopathic Deviate
Mf = Masculinity/Femininity
Pa = Paranoia
Ps = Psychasthenia
Sc = Schizophrenia
Ma = Mania
Si = Social Introversion
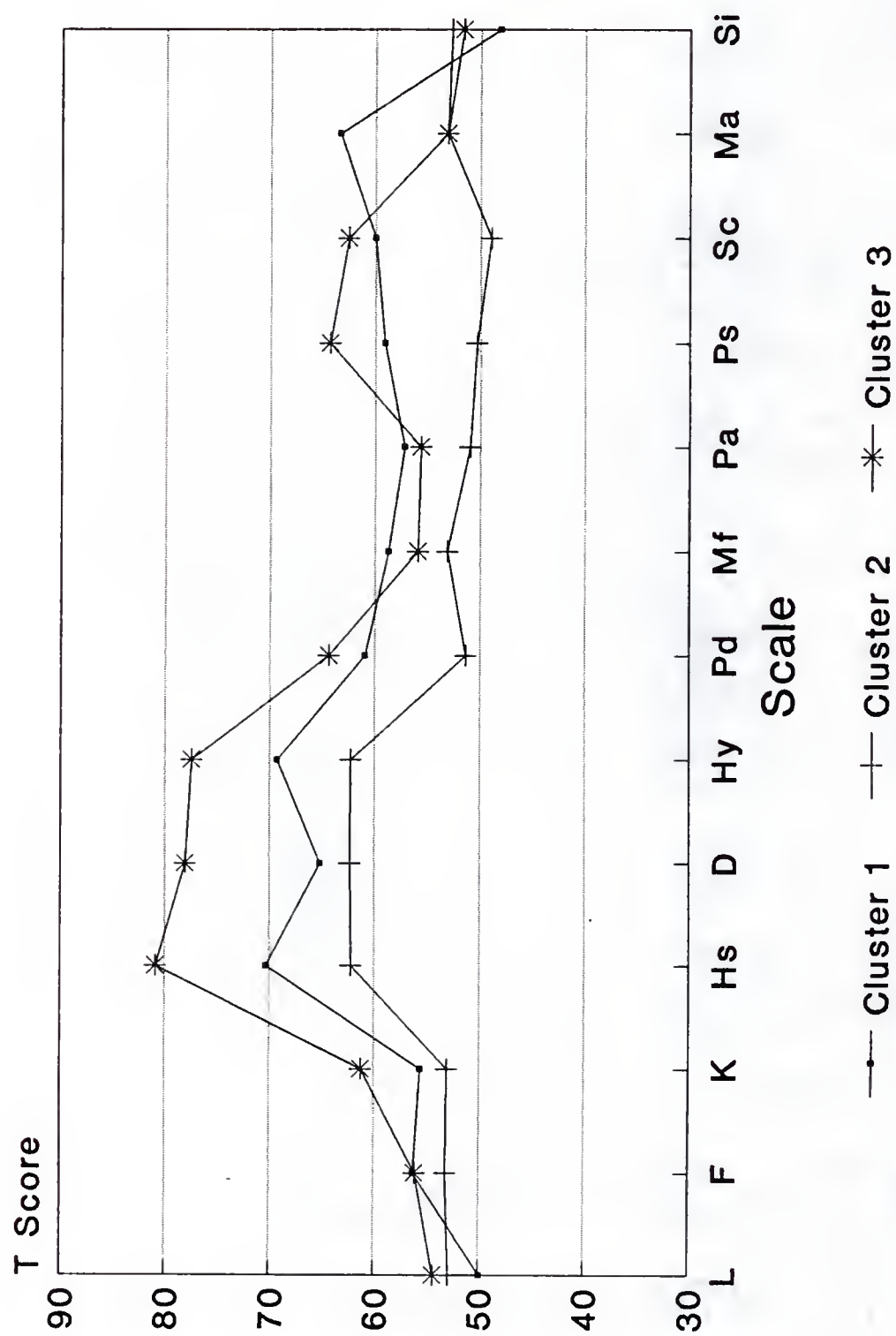
Table 6

Mean Recipient Quality of Life Ratings by Cluster Group

	Cluster 1[a]		Cluster 2[b]		Cluster 3[c]	
Variable	$\underline{M}$	$\underline{s}$	$\underline{M}$	$\underline{s}$	$\underline{M}$	$\underline{s}$
Symptom Report						
Problem Total	4.39	4.23	3.81	3.72	5.26	4.63
Frequency	8.74	5.80	9.52	4.62	10.84	5.29
Satisfaction Report (SWLS)						
Life	24.79	7.70	23.23	7.39	23.83	6.89
Health Report (SF-36)						
Physical Function	72.50	23.50	76.36	21.45	69.57	22.25
Mental Health	75.67	14.59	71.27	18.99	72.00	23.24
General Health	61.54	23.06	63.00	28.90	60.51	23.27

[a]$\underline{n}$ = 24. [b]$\underline{n}$ = 22. [c]$\underline{n}$ = 35.

tested is unrelated to post-transplantation functioning. However, increased post-transplantation hospitalization time is associated with increased symptom reporting and decreased mental health.

The same order of analyses was conducted using the spouse/proxy ratings on the quality of life measures. The results from MANCOVAs with the Symptom Report as the dependent variable were consistent with the recipients', such that no significant differences were found between cluster groups [F (2, 60) = .97, p > .05]. Results from tests using the Problem Total as the dependent variable found no significant differences for the cluster groups F (2, 34) = .04, p > .05]. On the Satisfaction report, the cluster groups were found to be not significantly different [F (2, 59) = .07, p > .05].

The final three MANCOVA procedures using the spouse/proxy Health Report found no significant differences for the clusters groups on Physical Functioning [F (2, 60) = .47, p > .05], Mental Health [F (2, 59) = .33, p > 05]., or General Health [F (2, 60) = .83, p > .05]. However, time since transplantation (p < .05) was a significant covariate for Physical Functioning, such that increased time since transplantation was associated with decreased physical functioning. Analyses using these covariates in alternative comparisons were found to be non-significant. In sum, the findings from these comparisons provide no evidence for MMPI cluster membership differences on post-transplantation functioning for the three groups tested using either recipient or spouse/proxy raters. The means for

each of the cluster groups on the spouse/proxy ratings of quality of life measures are available in Table 7.

Regression Analyses

A second primary purpose of this study was to examine the possibility of variables serving as "markers" for prediction of quality of life. Stepwise regression analyses were utilized to examine this possibility. Using the 6 dependent variables of quality of life, the variables of the medical domain (e.g., time since transplantation, ejection fraction, duration of disease, and post-transplantation hospitalization time) and the psychological domains (e.g. Trait Anxiety, Trait Anger, and Depression scores) were entered to determine which variables accounted for unique variance. Each analysis was performed in an identical, stepwise fashion with the variable accounting for the most variance being entered first, followed by additional significant variables in descending order of variance accounted for by the independent variable. Missing variables were handled pairwise, such that all possible variables with valid values on the variables being compared were included in the analysis. The stepwise procedure was selected because no order of entry was predicted. This procedure was thought to maximize the possibility of finding a predictor in the least number of analyses.

Symptom Frequency was the first dependent variable used in the regression analyses. Trait Anxiety was the first variable entered into the equation [F (1, 37) = 11.75, p < .01], accounting for 24% of the variance. No other predictor variables entered the regression equation. The next

Table 7

Mean Spouse/Proxy Quality of Life Ratings by Cluster Group

Variable	Cluster 1[a]		Cluster 2[b]		Cluster 3[c]	
	M	s	M	s	M	s
Symptom Report						
Problem Total	3.67	4.17	4.00	3.74	4.30	4.40
Frequency	9.00	5.32	11.00	5.94	11.40	4.83
Satisfaction Report (SWLS)						
Life	23.68	7.17	24.33	5.97	24.48	7.99
Health Report (SF-36)						
Physical Function	60.23	29.09	71.25	30.30	69.44	25.88
Mental Health	66.29	20.81	65.00	17.68	70.52	23.93
General Health	57.95	33.87	64.94	21.48	54.26	29.60

[a]n = 22. [b]n = 22. [c]n = 27.

dependent variable examined was the Problem Total score. Once again, only Trait Anxiety entered the equation [$F_{(1, 37)} = 5.64$, $p < .05$], accounting for 13% of the variance. The third regression analysis involved the prediction of the Satisfaction report. However, no significant predictors were found.

The final three regression equations with the recipient ratings involved the Health Report variables. On the Physical Functioning measure, no significant predictors entered the model. Mental Health was examined next and Trait Anxiety entered the model [$F_{(1, 37)} = 11.47$, $p < .01$], accounting for 24% of the variance. No other variables entered the model. Finally, General Health was examined using regression analysis. Post-transplantation hospitalization entered the model [$F_{(1, 37)} = 4.34$, $p < .05$] accounting for approximately 11% of the variance. No additional variables entered the model for General Health.

Spouse/Proxy Regression Analyses

The spouse/proxy ratings were examined in an identical fashion to the recipients' ratings using regression analyses. The medical variables of time since transplantation, ejection fraction, duration of disease, and post-transplantation hospitalization and the psychological variables of Trait Anxiety, Trait Anger, and Depression were used as the independent variables. Symptom Frequency was used as the first dependent variable, however, no significant predictors were found. Similarly, no significant predictors were found for Problem Total. The Satisfaction report was the

third regression analysis performed. Trait Anxiety entered the model [F (1, 29) = 6.05, p < .05] and accounted for 17% of the variance in life satisfaction. No other variables were found as significant predictors.

In the regression equations using Physical Functioning as the dependent variable, no significant predictors were found. However, in regression equations using the Mental Health score as the dependent variable, Trait Anxiety entered the model [F (1, 30) = 4.93, p < .05], accounting for 14% of the variance. No other significant predictors were found. Finally, General Health was tested for possible predictor variables but no significant predictors were found.

Comparisons of Quality of Life (Recipients vs. Spouses/Proxies)

Correlations. Pearson's correlational coefficients were computed between recipients and their spouse/proxies for each of the quality of life variables and all correlations were statistically significant at the p < .0001 level, except for the Problem Total. Recipients and spouse/proxies corresponded highly on the frequency of symptoms (r = .71, p < .0001) but the Problem Total was not significant (r = .20, p < .09). This discrepancy was somewhat expected because the Problem Total score was the only set of questions that asked for the spouse/proxies to report how the recipient impacted them personally. The Satisfaction Report from the recipient and spouse/proxies was consistent (r = .59, p < .0001), suggesting a high degree of agreement between the recipient and spouse/proxy views of the recipient's overall life satisfaction. Finally, the indices of the Health Report

were each highly consistent between recipient and spouse/proxies yielding significant correlations in Physical Functioning (r = .57, p < .0001), Mental Health (r = .54, p < .0001), and General Health (r = .51, p < .0001).

Planned Comparisons. T-tests were used to compare the mean ratings on each of the quality of life indices for significant differences between recipients and the spouse/proxies. A total of 6 comparisons were made and Bonferonni corrections were made to control for family-wise error rate. The means are slightly different for the recipients' reports in these comparisons because only recipients with spouse/proxy raters were included in the analysis. Results indicated that significant differences were found between recipients and spouse/proxies in their views of the recipients' mental health [t (1, 66) = 2.37, p < .01], such that the spouse/proxies reported significantly more impairment in mental health functioning. Table 8 provides the means used in these comparisons. It is interesting to note that there were no differences found in the hypothesized direction in either role functioning related to physical health or role functioning related to mental health. In addition, no differences were found on Problem Total, which may have been expected given that the respondent's were asked to respond whether the symptom was a problem specifically for himself/herself and not the recipient.

Table 8

Quality of Life Means for Planned Comparisons

		Recipient		Proxy/Spouse	
Variable	$\underline{n}$	$\underline{M}$	$\underline{s}$	$\underline{M}$	$\underline{s}$
Symptom Report					
Problem Total	37	4.68	3.87	3.78	3.64
Frequency	40	10.08	5.49	10.68	5.28
Satisfaction Report (SWLS)					
Life	66	23.41	7.51	23.94	7.19
Health Report (SF-36)					
Physical Function	67	72.99	23.28	67.46	27.98
Mental Health	66	72.79	17.12	67.33	21.14
General Health	67	60.43	23.39	58.63	28.99

DISCUSSION

The purpose of the present study was four-fold: 1) to provide descriptive information about the prevalence of immunosuppressive symptomatology and quality of life of cardiac transplantation recipients, 2) to test the predictive validity of a pre-transplantation psychological assessment battery on the recipient's perceived post-transplantation quality of life, 3) to test the predictive validity of the pre-transplantation psychological assessment battery on the perceived post-transplantation quality of life by spouse/proxy, and 4) to assess the correspondence of the recipient and spouse/proxy raters on quality of life.

The results from descriptive analyses of the recipients' quality of life indicated that on average, cardiac transplantation recipients commonly experience approximately 10 symptoms. The most frequent and problematic symptom for the recipients was fatigue. According to spouse/proxy reports, excessive hair growth was reported as the most frequent symptom, but mood swings were rated as the most problematic for the spouse/proxies. The spouse/proxy findings were similar to previous research that found excessive hair growth as the most common symptom for patients on a cyclosporine regimen (Lough et al., 1987). Additional descriptions of the recipients' quality of life were obtained from the Satisfaction and Health

93

Reports, which found that the recipients were generally as satisfied and healthy as comparable general populations (Pavot & Diener, 1993).

The predictive validity of the MMPI was tested by two methods including: cluster analyses followed by MANCOVAs and stepwise regression analyses. First, cluster groups were formed and MANCOVA analyses were tested. The four-cluster solution presented by Robinson et al. (1993) of a smaller sample of cardiac transplantation candidates was generally replicated. However, the "High Distress" cluster was renamed the "Distressed/Confused" cluster to reflect the generally more clinically elevated profile that was found. Interestingly, this group was found to contain only one transplantation recipient and was unable to be entered in future analyses. This finding suggests that persons in this cluster group may be "screened out" by the transplantation review committee due to recognized concerns of the transplantation team or may not have survived transplantation and the follow-up period. The loss of the "Distressed/Confused" cluster appeared to reduce the range of possible variability across cluster groups. In the MANCOVA procedures, no significant differences were found between cluster groups using post-transplantation hospitalization time and time since transplantation as covariates and the quality of life dimensions as the dependent variables. The loss of the unrepresented cluster group may explain this finding because the most distressed group could not be included in comparisons. The second method used to test the predictive validity was stepwise regression analyses. The medical variables listed above and the psychological variables

of Trait Anxiety, Trait Anger, and the Beck Depression Inventory were used as independent variables. Results from these analyses found that Trait Anxiety was a significant predictor of the recipient reports on Symptom Frequency, Problem Total, and Mental Health. These data suggest that a candidate's anxiety proneness may relate to his or her tendency to experience symptoms and report problem symptoms associated with the immunosuppressive regimen in the post-transplantation period. Similarly, a person's disposition toward anxiety was found to be associated with post-transplantation mental health functioning, thus supporting the utility of measuring Trait Anxiety at the pre-transplantation evaluation.

The predictive validity of the pre-transplantation data was also tested using the spouse/proxy reports. The results revealed some consistency with the recipient results. Specifically, Trait Anxiety was found to be a significant negative predictor of Mental Health and Life Satisfaction. Collectively, Trait Anxiety emerged as a powerfully, diverse predictor of post-transplantation quality of life functioning, as viewed from both the recipient and spouse/proxy perspective.

The final major purpose of this study examined the correspondence between recipient and spouse/proxy ratings of quality of life. Results from correlational analyses found that all quality of life variables were significantly correlated, with the exception of the Problem Total score. Follow-up planned comparisons found that significant differences existed between the recipient and spouse/proxy ratings on Mental Health. These findings

suggest that recipient and spouse/proxy raters generally share highly similar views of the recipient's functioning, with the exception of mental health. The significant difference in mental health functioning can be viewed as consistent with the findings related to Symptom Frequency in which the spouse/proxies rated symptoms such as mood swings in a very different way. Specifically, recipients reported less frequent and less problematic mood swings. These findings are consistent with the conclusions of Sprangers and Aaronson (1992) who suggested that the level of agreement between patients' self-reports and significant other's ratings was dependent on the concreteness, visibility, and subjectivity of the dimensions being assessed. These authors concluded that there is a tendency for significant others to rate more negatively the quality of life and functioning of the patient.

The pre-transplantation variable that plays the most prominent role in this study across analyses is Trait Anxiety. First, Trait Anxiety was significantly different between the recipients and candidates. Trait Anxiety was then found to be a significant predictor of mental health (both recipient and spouse/proxy report), Life Satisfaction (spouse/proxy report), and Symptom Frequency and the degree to which these symptoms were viewed as problematic. These findings are contrasted with a study of CABG patients in which anxiety was found to be unrelated to a measure of quality of life (Conn, Taylor, & Wilman, 1991). The specificity of the operationalization of quality of life in the current study allows us to assert

more strongly what aspects of quality of life (symptomatology, satisfaction, and mental health) anxiety was related.

The relationship between anxiety and somatic complaints has an extensive history in clinical psychology in both the anxiety disorder literature (e.g., somatoform pain disorder) as well as the behavioral medicine literature (e.g., anxiety in patients undergoing medical procedures). Anxiety has specifically been examined in the cardiac disease literature as part of the Type A construct (Matthews, 1988) and has been linked in numerous studies to increased somatic complaints and chest pain (Costa & McCrae, 1987). These authors have concluded that neuroticism (anxiety, depression, and hostility) is responsible for increased somaticism, even after controlling for age or aging. Similar conclusions were drawn by Blumenthal and his colleagues (1979) after examining the relationship between chest pain and angiographic results in which trait anxiety predicted less actual disease process. This finding should not be interpreted as evidence of no disease processes in the recipients, but rather a tendency to report and be responsive to symptom sensations.

The impact of anxiety in transplantation recipients remains difficult to pinpoint. The findings from the current study would appear to support a more extensive examination of anxiety in these patients. However, the health psychology literature would suggest that the relationship between any single component of negative affect (anxiety, anger, and depression) and any health outcome (morbidity or mortality) probably is a complex one.

Evidence for either the inclusion or exclusion of any negative affect
component seems to be available in the research literature. Depression has
received the most extensive research attention but has not led to any firm
conclusions about its role in medical and quality of life outcomes. Research
has examined the logical hypothesis that negative affect may be related to
the degree of medical distress (Maricle et al., 1991). However, no current
evidence is available to support this view. Depression has also been
examined as a possible negative "marker" for long-term outcome. Studies
with both renal transplantation recipients and bone marrow transplantation
recipients have supported the notion of the long-term negative impact of
depressive presentations on quality of life (Colon et al. 1991; Rodin &
Voshart, 1987). However, other studies, such as Maricle et al. (1991),
found no relationship between cardiac function and depressive symptoms in
a sample of cardiac transplantation recipients.

There are many possible explanations for these differing results.
It is our view that much of the instability of the findings is related to the
different measurement practices of researchers in operationalizing both the
negative affect variables as well as the outcome measures (mortality, cardiac
function, and quality of life). One remedy would include establishing more
systematic protocols or assessment batteries that would lead to more
collaboration across settings. Another potential antagonist is the similarity
or collinearity of the measured constructs. Matthews (1988) has suggested
that anger, anxiety, and depression may reflect a single dimension efficiently

described as negative affect and may lead to a disease-prone personality. Therefore, a possible interpretation, consistent with these lines of reasoning, was that Trait Anxiety was the most stable construct measured in this study and resulted in the lowest available measure of error. Perhaps, the Beck Depression Inventory really is measuring only "state depression" and does not perform well in long-term follow-up studies such as the current study. Therefore, Trait Anxiety was able to maintain the strongest relationship to our quality of life measures across time because the questionnaire measured its construct consistently. Although this debate may be circular, a clinical implication for this finding includes the close examination of pre-morbid and early onset psychological functioning (trait functioning) as a predictor of post-transplantation functioning.

Anxiety may also have emerged in this study because of the importance of anxiety to pain perception. Anxiety has been suggested to affect pain perception through a variety of means and has been included in cognitive behavioral models for pain perception. For example, Hanson and Gerber (1990) reviewed a pain perception model that involved at least four interacting components: the perception of bodily symptoms, a perception of what the symptom means, the manner in which these symptoms are expressed, and what the individual does to cope with these symptoms. In light of the present findings, it is suggested that Trait Anxiety could affect virtually any one of those steps of perception of pain or somatic complaints. For example, the experience of anxiety often includes increased heart rate, sweating, tremors, and respiration. If a transplantation recipient experiences

these symptoms, he or she must make some attribution about its cause, "Is my heart racing because I'm anxious or because I'm getting sick again?" Therefore, the occurrence of symptoms associated with anxiety (e.g., increased heart rate and respiration) must be understood and contended with in some way. Persons reporting high levels of Trait Anxiety are likely to be disturbed by the experience of increased symptoms following transplantation and may seek medical attention more frequently. Simply the sheer number of new somatic sensations associated with the transplantation procedure and subsequent medication regimen could be overwhelming for the anxious recipient. The results of our study would suggest that the typical recipient would be regularly affected by an average of 10 symptoms that would require the person to undergo the four steps of processing somatic experience.

The lack of findings with regard to the MMPI cluster types was somewhat surprising. The most obvious interpretation was that the exclusion of the most distressed group due to small sample size reduced the range of potential variability between groups. It can only be supposed that this group would have been significantly different, since systematic analyses were impossible. However, the clinical decision-making by the medical review board may have excluded these persons for such reasons as a history of medical non-compliance, substance abuse, significant psychopathology, etc.

The similarities and discrepancies of the recipient and spouse/proxy ratings support the view of general agreement and concurrent validation. Recipients and their spouse/proxies seem to have similar perspectives on the functioning of the recipient. Consistent with the proxy literature, the direction of the discrepancies usually involve the spouse/proxy rating the functioning slightly lower than the patient. These tendencies were borne out in our study with the Mental Health score but similar trends were not found in analyses focused on role limitations due to physical and mental problems.

The ethical issues in the selection of transplantation recipients remain a difficult area for all health professionals and warrant much consideration. The data from transplantation studies, such as the current study, should be interpreted with a degree of caution and a full recognition of the value-laden nature of applying the findings to the clinical setting. For example, the data can be easily misused to support views for the exclusion of patients seen as "neurotic" or "complainers." Kilner (1990) has extensively reviewed the pros and cons of selection criteria, such as psychological ability, for allocation of scarce medical resources such as organ transplants. Psychological ability was defined by Kilner to include such aspects as: the intellectual and emotional capacity to cope with treatment or with life in general, the willingness to cooperate with treatment, and the ability to benefit from the medical intervention.

Kilner (1990) provided data from a sample of transplantation directors that found 97% of the directors considered information related to the above

psychological criteria and the information was considered "somewhat important" in their decision-making. He suggested that the clearest and broadest support for psychological ability criteria is found in cases where the patient would not benefit medically from the treatment. Furthermore, Kilner suggested that psychological criteria should constantly be evaluated for its relevance to the constantly changing technology. For example, if the post-transplantation regimen were to become less psychologically and behaviorally demanding, then psychological factors would become less relevant. Additional guidelines, such as trial periods of compliance with medical regimens, can provide "in vivo" tests of whether a patient has the capacity to adhere to the prescribed regimen. Kilner concluded that psychological ability criteria are not likely to be widely accepted as a means of exclusion but may be used as a piece of evidence of likely medical benefit. The current data were collected for the purpose of including such candidates with more "difficult" dispositions and providing intervention at both the pre- and post-transplantation stages to facilitate successful quality of life outcomes (see below). Despite the temptation to use any information about a patient that would signal a less than excellent post-transplantation prognosis as evidence against the distribution of a scarce resource as a cardiac transplant, this data is best used as "markers" signaling intervention and inclusion, rather than exclusion.

Several strengths of this study deserve mention. First, this study operationalized quality of life using a multiple criteria approach. This strategy provided different types of information that provide a "mosaic"

view of quality of life. Similarly, the use of both recipient and spouse/proxy reports to view quality of life provided convergent validity on the information of critical interest. The current health care reform debates appear to be searching for information about the resulting quality of life that medical treatments, such as cardiac transplantation, can deliver. Studies using similar research strategies will provide reliable data for decision-making. Another particular strength to this study is the practical information of baserates of symptomatology related to the immunosuppressive regimen in a sample of recipients at various intervals since transplantation. Perhaps, the most important strength of this study was its use of a longitudinal design. The long-term impact of cardiac transplantation continues to be explored but studies such as this provide the first glimpses of predicting the long-term quality of life for cardiac transplantation recipients.

This study also suffers from some limitations that should be taken into account when interpreting its results. Selection pressures are a pervasive influence in working with medical patients such as heart transplantation recipients. More specifically, selective attrition due to pre-transplantation "screening" or death may leave only a truncated range of quality of life among survivors. A second limiting factor involves the relatively small sample size included in this study. Although all potential subjects were contacted at one of the most active transplantation centers in the United States, the sample size would not be considered "large" on stringent statistical grounds. Thus, related problems such as low gender and cultural diversity are also present in the current sample. Although statistical tests

found no impact for demographic variables, a more complete test of the role of demographic variables should be tested with larger samples in the future. Finally, a variable that was not included in the current study that may play a role in quality of life was financial status and insurance coverage. Clinically and anecdotally, this variable has had a powerful influence on the recipients' perceived support and/or burden. The financial burden of transplantation is well-established as being extraordinary from pre-transplantation evaluation to long-term medication support. Future research may want to determine ways of including the concurrent financial burden with recipient quality of life to examine possible relationships over time.

The clinical relevance of this investigation was a central impetus for its completion. Despite several caveats in interpretation related to the weaknesses of the study, several clinical recommendations follow from the findings. First, careful attention should be provided to transplantation candidates with profiles consistent with the "Distressed/Confused" cluster to determine on what grounds or at what stage they are being excluded from the transplantation pool. Is it that they are being rejected at pre-transplantation or are they having difficulty with post-transplantation? The current study simply demonstrated that they are being excluded at some stage of transplantation. However, no data were presented that would support a systematic reason for this exclusion. Second, transplantation candidates that report high levels of Trait Anxiety are likely to report increased symptoms and decreased mental health during the post-transplantation period if no interventions are provided. Although the findings

are correlational in nature, the current data can be used to support a systematic intervention with high trait anxious patients at the pre-transplantation stage in order to maximize their reports of quality of life in later stages. Interventions that provide support for the expression of both negative affect and symptom complaints in terms of normalization, prediction, and control would assist the anxious patient to adjust to the new somatic sensations associated with the post-transplantation regimen. The use of coping strategies, such as reinterpretation of pain and coping self-statements, would help to reduce the possibility of catastrophizing at the presence of certain types of symptoms. Collectively, these interventions could be tailored to facilitate adaptation and coping for these patients with the intention of enhancing their quality of life.

Cardiac transplantation remains an exciting development of current medical technology that can sustain life. This study has attempted to consider quality of life as an equally suitable outcome of transplantation. In general, transplantation recipients appear to be functioning with good to excellent quality of life that encompasses symptoms, satisfaction, and health. Although the prediction of quality of life longitudinally remains a difficult task, continued use and refinement of pre-transplantation assessment batteries is warranted to attempt to predict successful outcomes in terms of quality of life. Ultimately, these data will lead to targeted interventions that aid all recipients and enhance their quality of life.

REFERENCES

Aaronson, N. K. (1986). Methodological issues in psychosocial oncology with special reference to clinical trials. In V. Ventafridda, F.S.A.M. Van Dam, R. Yancik & M. Tamburini (Eds.) <u>Assessment of quality of life and cancer treatment</u>. Amsterdam: Excerpta Medica.

Baker, F., Curbow, B., & Wingard, J. R. (1991). Role retention and quality of life of bone marrow transplant survivors. <u>Social Science Medicine</u>, <u>32</u>(6), 697-704.

Barofsky, I. (1986). Quality of life assessment: Evolution of the concept. In V. Ventafridda, F. S. A. M. Van Dam, R. Yancik & M. Tamburini (Eds.) <u>Assessment of quality of life and cancer treatment</u>. Amsterdam: Excerpta Medica.

Beidel, D. C. (1987). Psychological factors in organ transplantation. <u>Clinical Psychology Review</u>, <u>7</u>, 677-694.

Blumenthal, J. A., Thompson, L. W., Williams, R. B., & Kong, Y. (1979). Anxiety-proneness and coronary heart disease. <u>Journal of Psychosomatic Research</u>, <u>23</u>, 17-21.

Brannon, F. J., Foley, M. W., Starr, J. A., & Black, M. G. (1993). <u>Cardiopulmonary rehabilitation: Basic theory and application</u>. Philadelphia: F.A. Davis Co.

Braunwald, E. (1992). The history. In E. Braunwald (Ed.), <u>Heart disease</u> (4th ed., pp. 1-12). Philadelphia, PA: W.B. Saunders Co.

Bremer, B. A., & McCauley, C. R. (1986). Quality of life measures: Hospital interview versus home questionnaire. <u>Health Psychology</u>, <u>5</u>(2), 171-177.

Brennan, A. F., Davis, M. H., Bucholz, D. J., Kuhn, W. F., & Gray, L. A. (1987). Predictors of quality of life following cardiac transplantation. <u>Psychosomatics</u>, <u>28</u>, 566-571.

Brook, R. H., Ware, J. E., & Davies-Avery, A. (1979). Conceptualization and measurement of health for adults in the health insurance study. Rand Technical Reports, 8, overview.

Bunzel, B., Grundbock, A., Laczkovicl, A., Holzinger, C., & Teufelsbauer, H. (1991). Quality of life after orthotopic heart transplantation. The Journal of Heart and Lung Transplantation, 10,(3), 455-459.

Buse, S., & Pieper, B. (1990). Impact of cardiac transplantation on the spouse's life. Heart and Lung, 19, 641-648.

Caine, N., Sharples, L. D., English, T. A. & Wallwork, J. (1990). Prospective study comparing quality of life before and after heart transplantation. Transplantation Proceedings, 22(4), 1437-1439.

Calman, K. C. (1984). Quality of life in cancer patients: A hypothesis. Journal of Medical Ethics, 10, 124-127.

Christopherson, L., & Lunde, D. (1971). Selection of cardiac transplantation recipients and their subsequent psychosocial adjustment. Seminars in Psychiatry, 3, 36-41.

Colon, E. A., Callies, A. L., Popkin, M. K., & McGlave, P. B. (1991). Depressed mood and other variables related to bone marrow transplantation survival in acute leukemia. The Academy of Psychosomatic Medicine, 32(4), 420-425.

Conn, V. S., Taylor, S. G., & Wilman, P. (1991). Anxiety, depression, quality of life, and self-care among survivors of myocardial infarction. Issues in Mental Health Nursing, 12, 321-331.

Costa, P. T. & McCrae, R. R. (1987). Role of neuroticism in the perception and presentation of chest pain symptoms and coronary artery disease. In J. W. Elias & P. H. Marshall (Eds.), Cardiovascular Disease and Behavior (pp. 39-66). Washington, DC: Hemisphere.

Dahlstrom, W. G., Welsh, G. S., & Dahlstrom, L. E. (1972). An MMPI handbook (Vols. I, II). Minneapolis: University of Minnesota Press.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. Journal of Personality Assessment, 49, 71-75.

Diener, E., Magnus, K., & Fujita, F. (1991). A longitudinal examination of life events and subjective well-being. Unpublished manuscript.

Eaker, E. D. (1989). Psychosocial factors in the epidemiology of coronary heart disease in women. Psychiatric Clinics of North America, 12, 167-173.

Epstein, A. M., Hall, J. A., Tognetti, J., Son, L. H., & Conant, L. (1989). Using proxies to evaluate quality of life. Medical Care, 27, S91-S98.

Freeman, A. M., Folks, D. G., Sokol, R. S., & Fahs, J. F. (1988). Cardiac Transplantation: Clinical correlates of psychiatric outcome. Psychosomatics, 29(1), 47-54.

Gray, H., Brogan, D., & Kutner, N. G. (1985). Status of life areas: Congruence/noncongruence in ESRD patient and spouse perceptions. Social Science and Medicine, 4, 341-346.

Green, C. J. (1985). The use of psychodiagnostic questionnaires in predicting risk factors and health outcomes. In P. Karoly (Ed.), Measurement strategies in health psychology. New York: Wiley.

Greene, A. F. (1992, August). Longitudinal issues in the adjustment of adult cardiac transplant recipient. Paper presented at the Annual Meeting of the American Psychological Association, Washington, DC.

Greene, A. F., Sears, S. F., & Mills, R. M. (1993). Personality and cognitive adaptation in the first year of cardiac transplantation: A typical case. Unpublished manuscript.

Guyatt, G., Feeny, D., & Patrick, D. (1991). Issues in quality of life measurement in clinical trials. Controlled Clinical Trials, 12, 81S-90S.

Hanson, R. W., & Gerber, K. E. (1990). Coping with chronic pain: A guide to patient self-management. New York: Guilford Press.

Hathaway, S. R., & McKinley, J. C. (1967). The Minnesota Multiphasic Personality Inventory manual. New York: Psychological Corp.

Haynes, S. G., & Czajkowski, S. M. (1993). Psychosocial and environmental correlates of heart disease. In P. S. Douglas (Ed.), Cardiovascular health and disease in women (pp. 269-282). Philadelphia, PA: W.B. Saunders Co.

Hecker, J. E., Norvell, N., & Hills, H. (1989). Psychological assessment of candidates for heart transplantation: Toward a normative data base. Journal of Heart Transplantation, 8, 171-176.

Jones, B. M., Chang, V. P., Esmore, D., Spratt, P., Shanahan, M. X., Farnsworth, A. E., Keogh, A., & Downs, K. (1988). Psychological adjustment after cardiac transplantation. The Medical Journal of Australia, 149, 118-122.

Jones, B. M., Taylor, F., Downs, K., & Spratt, P. (1992). Longitudinal study of quality of life and psychological adjustment after cardiac transplantation. Medical Journal of Australia, 157(1), 24-26.

Kay, J., & Bienenfeld, D. (1991). The clinical assessment of the cardiac transplant candidate. Psychosomatics, 32, 78-87.

Kaye, M. P. (1993). The registry of the International Society for Heart Transplantation: Ninth official report-1992. The Journal of Heart Transplantation, 14, 599-606.

Kilner, R. (1992). Who lives? Who dies? Philadelphia, PA: W.B. Saunders Co.

Kriett, J. M., & Kaye, M. P. (1990). The registry of the International Society for Heart Transplantation: Seventh official report-1990. The Journal of Heart Transplantation, 9, 323-330.

Kuchler, T., Kober, B., Brolsch, C., Henne-Bruns, D., & Kremer, B. (1991). Quality of life after liver transplantation: Can a psychosocial support program contribute? Transplantation Proceedings, 23(1), 1541-1544.

Kuhn, W. F., Davis, M. H., & Lippman, S. B. (1988). Emotional adjustment to cardiac transplantation. General Hospital Psychiatry, 10, 108-113.

Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. Handbook of Behavioral Medicine, 282-325.

Lee, D., Mendes De Leon, C. F., Jenkins, C. D., Croog, S. H., Levine, S., & Sudilovsky, A. (1992). Relation of hostility to medication adherence, symptom complaints, and blood pressure reduction in a clinical field trial of antihypertensive medication. Journal of Psychosomatic Research, 36(2), 181-190.

Lorell B. H., & Braunwald, E. (1992). Pericardial disease. In E. Braunwald (Ed.), Heart disease (4th ed., pp. 1456-1516). Philadelphia, PA: W.B. Saunders Co.

Lough, M. E., Lindsey, A. M., Shinn, J. A., & Stots, N. A. (1987). Impact of symptom frequency and symptom distress on self-reported quality of life in heart transplant recipients. Heart and Lung, 16, 193-200.

MacKiegan, L. S., & Pathak, D. S. (1992). Overview of health-related quality of life measures. American Journal of Hospital Pharmacy, 49, 2236-2245.

Magaziner, J., Simonsick, E. M., Kashner, T. M., & Hebel, J. R. (1988). Patient-proxy response comparability on measures of patient health and functional status. Journal of Clinical Epidemiology, 41(11), 1065-1074.

Mai, F. M., McKenzie, F. N., & Kostuk, W. J. (1990). Psychosocial adjustment and quality of life following heart transplantation. Canadian Journal of Psychiatry, 35, 223-227.

Maricle, R. A., Hosenpud, J. D., Norman, D. J., Pantley, G. A., Cobanoglu, A. M., & Starr, A. (1991). The lack of predictive value of preoperative psychologic distress for postoperative medical outcome in heart transplant patient. Journal of Heart and Lung Transplantation, 10, 942-947.

Maricle, R. A., Hosenpud, J. D., Norman, J. D., Woodbury, A., Pantley, G. A., Cobanoglu, A. M., and Starr, A. (1989). Depression in patients being evaluated for heart transplantation. General Hospital Psychiatry, 11, 418-424.

Matthews, K. A. (1988). Coronary heart disease and type a behaviors: Update on and alternative to the Booth-Kewley and Friedman (1987) quantitative review. Psychological Bulletin, 104(3), 373-380.

Mayou, R. (1990). Quality of life in cardiovascular disease. Special issue: Quality of life in the medically ill: A psychosomatic approach. Psychotherapy and Psychosomatics, 54(2-3), 99-109.

Mersch, J. (1985). End-stage cardiac disease: Cardiomyopathy. In M.K. Douglas & Shinn, J. A., Advances in cardiovascular nursing. Rockville, MD: Aspen Publishing. 117-139.

Mishel, M. H., & Murdaugh, C. L. (1987). Family adjustment to heart transplantation: Redesigning the dream. Nursing Research, 36, 332-338.

O'Brien, B. J., Banner, N. R., Gibson, S. & Yacoub, M. H. (1988). The Nottingham Health Profiles as a measure of quality of life following combined heart and lung transplantation. The Journal of Epidemiology and Community Health, 42, 232-234.

Packa, D. R. (1989). Quality of life of adults after a heart transplant. Journal of Cardiovascular Nursing, 3(2), 12-22.

Paris, W., Woodbury, S., Thompson, S., Levick, M., Nothegger, S., Hutkin-Slade, L., Arbuckle, P., & Cooper, D. K. C. (1992). Social rehabilitation and return to work after cardiac transplantation: A multi-center survey. Transplantation, 53, 433-438.

Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: Gender and the psychological costs of caregiving. American Journal of Orthopsychiatry, 61, 501-509.

Pavot, W., & Diener, E. (1993). Review of the satisfaction with life scale. Psychological Assessment, 5, 164-172.

Rabinowitz, S. & Van-der Spuy, H. I. (1978). Selection criteria for dialysis and renal transplant. American Journal of Psychiatry, 135(7), 861-863.

Robinson, M. E., Greene, A. F., & Geisser, M. E. (1993). Specificity of MMPI cluster types to chronic illness. Psychology and Health, 8, 285-294.

Rodin, G., & Voshart, K. (1987). Depressive symptoms and functional impairment in the medically ill. General Hospital Psychiatry, 9, 251-258.

Ryan, J. J., Larsen, J., & Prifitera, A. (1983). Validity of the Two and four-subtest short forms of the Wechsler Adult Intelligence Scale-Revised in a psychiatric sample. Journal of Consulting and Clinical Psychology, 51, 460.

Scharlach, A. E., Sobel, E. L., & Roberts, R. E. L. (1991). Employment and caregiver strain: An integrative model. Gerontologist, 31, 778-787.

Schipper, H., & Levitt, M. (1986). Quality of life in cancer trials: What is it? Why measure it? In V. Ventafridda, F. S. A. M. Van Dam, R. Yancik & M. Tamburini (Eds.) Assessment of quality of life and cancer treatment. Amsterdam: Excerpta Medica.

Schocken, D. D., Greene, A. F., Worden, T. J., Harrison, E. E., & Spielberger, C. D. (1987). Effects of age and gender on the relationship between anxiety and coronary artery disease. Psychosomatic Medicine, 49(2), 118-125.

Sechrest, L., & Pitz, D. (1987). Commentary: Measuring the effectiveness of heart transplant programmes. Journal of Chronic Diseases, 40, 155S-158S.

Shapiro, P. A. (1990). Life after heart transplantation. Progress in Cardiovascular Disease, 32(6), 405-418.

Shapiro, P. A., & Kornfeld, D. S. (1989). Psychiatric outcome of heart transplantation. General Hospital of Psychiatry, 11, 352-357.

Silverstein, A. B. (1982). Two and four-subtest short forms of the Wechsler Adult Intelligence Scale-Revised. Journal of Consulting and Clinical Psychology, 50(3), 415-418.

Spielberger, C. D. (1984). The State-Trait Anger Expression Inventory: Research edition. Odessa, FL: Psychological Assessment Resources.

Spielberger, C. D., Gorsuch, R. L., & Lushene, R. E. (1970). State-Trait Anxiety Inventory manual. Palo Alto, CA: Consulting Psychologists Press.

Sprangers, M. A. G., & Aaronson, N. K. (1992). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: A review. Journal of Clinical Epidemiology, 45(7), 743-760.

Spreen, O., & Strauss, E. (1991). A compendium of neuropsychological tests: Administration, norms, and commentary. New York: Oxford Press.

Stewart, A. L., Sherbourne, C. D., Hays, R. D., Wells, K. B., Nelson, E. C., Kamberg, C. J., et al. (1992). Summary and discussion of MOS measures. In A. L. Stewart, & J. E. Ware (Eds), Measuring functioning and well-being, (pp. 345-372). Durham, NC: Duke University Press.

Suszycki, L. H. (1988). Psychosocial aspects of heart transplantation. Social Work, May-June, 205-209.

Ware, J. E. (1993). SF-36 Health Survey: Manual and interpretation guide. Boston, MA: Nimrod Press.

Wechsler, D. (1945). A standardized memory scale for clinical use. Journal of Psychology, 19, 87-95.

Wynne, J., & Braunwald, E. (1992). The cardiomyopathies and myocarditides: Toxic, chemical, and physical damage to the heart. In E. Braunwald (Ed.), Heart disease (4th ed., pp.1392-1450). Philadelphia, PA: W.B. Saunders Co.

APPENDIX

TRANSPLANT SYMPTOM FREQUENCY QUESTIONNAIRE

Please think about the symptoms and conditions that affect you as a result of your heart transplant and daily medication regimen.

Next, I will read you a list of symptoms sometimes experienced by medical patients. Please indicate how often you experience each symptom by using the following choices:

0 = <u>Never</u> have symptom
1 = <u>Rarely</u> have symptom
2 = <u>Sometimes</u> have symptom
3 = <u>Often</u> have symptom
4 = <u>Always</u> have symptom

SYMPTOM	FREQUENCY	Is this a problem for you?
Varicose Veins	0 1 2 3 4	Yes No
Bad Breath	0 1 2 3 4	Yes No
Mood Swings	0 1 2 3 4	Yes No
Depression	0 1 2 3 4	Yes No
Lack of Sleep	0 1 2 3 4	Yes No
Fatigue	0 1 2 3 4	Yes No
Breathing	0 1 2 3 4	Yes No
Changed Facial Appearance	0 1 2 3 4	Yes No
Changed Bodily Appearance	0 1 2 3 4	Yes No
Excessive Hair Growth	0 1 2 3 4	Yes No
Acne	0 1 2 3 4	Yes No

Fragile Skin	0 1 2 3 4	Yes	No
Pain	0 1 2 3 4	Yes	No
Overeating	0 1 2 3 4	Yes	No
Poor Appetite	0 1 2 3 4	Yes	No
Diarrhea	0 1 2 3 4	Yes	No
Nausea	0 1 2 3 4	Yes	No
Taste	0 1 2 3 4	Yes	No
Swollen Ankles	0 1 2 3 4	Yes	No
Decreased Sexual Interest	0 1 2 3 4	Yes	No
Impotence (MEN)	0 1 2 3 4	Yes	No
Menstruation Monthly Periods (WOMEN)	0 1 2 3 4	Yes	No
Bruises	0 1 2 3 4	Yes	No
Headaches	0 1 2 3 4	Yes	No
Poor Concentration	0 1 2 3 4	Yes	No
Fever	0 1 2 3 4	Yes	No
Poor Vision	0 1 2 3 4	Yes	No
Heart Palpitations	0 1 2 3 4	Yes	No
Tremors	0 1 2 3 4	Yes	No

SATISFACTION WITH LIFE SCALE (SWLS)

Next, I would like to read you five statements with which you may agree or disagree. Please indicate your agreement or disagreement using the following scale:

1 = <u>Strongly Disagree</u>
2 = <u>Disagree</u>
3 = <u>Slightly Disagree</u>
4 = <u>Neither Agree nor Disagree</u>
5 = <u>Slightly Agree</u>
6 = <u>Agree</u>
7 = <u>Strongly Agree</u>

_____   1) In most ways my life is close to my ideal.

_____   2) The conditions of my life are excellent.

_____   3) I am satisfied with my life.

_____   4) So far I have gotten the important things I want in life.

_____   5) If I could live my life over, I would change almost nothing.

THE MOS 36-ITEM SHORT-FORM HEALTH SURVEY (SF-36)

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

Excellent	1
Very Good	2
Good	3
Fair	4
Poor	5

2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

Much better than one year ago	1
Somewhat better than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse than one year ago	5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

ACTIVITIES	Yes, Limited a Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities,** such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities,** such as moving a table, pushing a vacuum, bowling, or playing golf	1	2	3
c. **Lifting or carrying** groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. **Bending, kneeling, or** stooping	1	2	3
g. Walking **more than a mile**	1	2	3
h. Walking **several blocks**	1	2	3
i. Walking **one block**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

	Yes	No
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious?

	Yes	No
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work as **carefully** as usual	1	2

6. In the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks?

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. for each question, please give the one answer that comes closest to the way your have been feeling. 'How much of the time during the <u>past 4 weeks</u> -

	All of the time	Most of the time	A good Bit of the time	Some of the time	A Little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	1	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.?

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How TRUE or FALSE is <u>each</u> of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

BIOGRAPHICAL SKETCH

Samuel F. Sears, Jr., was born in Orlando, Florida, on June 21, 1968, to Samuel and Becky Sears. He was raised in the Central Florida area and graduated from Lake Brantley High School in Altamonte Springs, Florida, in June 1986. Samuel received his Bachelor of Science degree with honors in psychology from the University of Florida in May 1990. He continued his education at the University of Florida and received his Master of Science degree in clinical and health psychology in August 1992. Samuel married Staci Denise Evans in May 1993.
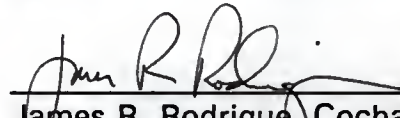
After completing the academic requirements for the Doctor of Philosophy degree, Samuel will complete his internship in clinical psychology at the University of Mississippi Medical Center and the Veterans Administration Medical Center in Jackson, Mississippi. Samuel enjoys spending time with his wife and family and remains an avid Gator fan. Samuel's future career goals include performing both clinical and research work at a major Southeastern university.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Hugh Davis, Chairman
Professor of Clinical
and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

James R. Rodrigue, Cochairman
Associate Professor of Clinical
and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Anthony F. Greene
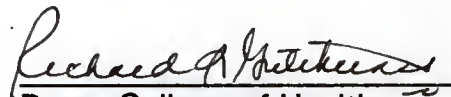Assistant Professor of Clinical
and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Eileen B. Fennell
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I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

John Newell
Professor of Foundations
of Education

This dissertation was submitted to the Graduate Faculty of the College of Health Related Professions and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August 1995

Dean, College of Health
Related Professions

Dean, Graduate School